TRANSITION TO PALLIATIVE CARE: FACILITATING ACTIONS FOR CANCER CLIENT-CENTERED COMMUNICATION

ABSTRACT

Introduction: the professional-client interpersonal relationship becomes fundamental in the transition to palliative care so that together they can improve communication at that time and align care to the client’s wishes. Objective: to analyze how the cancer client evaluates communication in the transition to palliative care; identify your needs and preferences regarding this communication related to your prognosis, decision making and family participation; and present a proposal for facilitating actions for communication in the transition to palliative care, based on the needs and preferences mentioned by the client. Method: convergent care research conducted at a federal hospital in Rio de Janeiro, with 15 cancer patients. A semi-structured interview was used, followed by a dialogue with each participant. Thematic analysis applied. Results: in the evaluation of the participants, the welcoming, the attentive way, the truth information and the simple and accessible language were essential elements to build a relationship of trust and enlightening communication about the moment lived. Still, clients were looking forward to more information about their treatment and prognosis. Although the majority mentioned the preference for the truth, family participation and active participation in the treatment, others demonstrated the preference for not knowing in order not to suffer, non-family participation and passivity in the participation in the treatment. Conclusion: it will be from the prioritization of active listening actions, welcoming, respect for autonomy and the use of clear and accessible language that the professional will create the necessary bond and be more successful in carrying out a communication centered on the needs and preferences of the cancer client.

Keywords: Medical Oncology; Communication; Palliative Care.
INTRODUCTION

Today, cancer remains one of the most complex public health problems, gaining prominence in health care due to its great potential for lethality, to occur in both developed and developing countries.¹

With technological and scientific advances and improvements in diagnosis and treatment, the number of cancer survivors has been increasing. However, the increase in this number contributes to a greater number of people living with cancer and its chronic and late effects, which ends up requiring a new reflection on the care models aimed at Oncology.²

It is in this context that palliative care emerges, which are designed for people who suffer with a life-threatening serious illness and, based on the identification, evaluation and treatment of pain and other physical, psychological, social and spiritual symptoms, aims to promote better quality of life for patients and their families, especially from good communication, through which it is possible to recognize and understand their needs.³,⁴

Considered an indispensable tool to provide individualized and quality care, communication is one of the pillars of great importance for palliative care. It is an especially needed skill in view of the worsening of the disease, especially in the transition to palliative care, as it allows the client to share his fears, sufferings and doubts, allowing conflicts to be resolved, offering adequate control of symptoms, in addition to provide an understanding of the client’s real needs.⁵,⁶

In this phase of transition from curative to palliative care, communicating the progress of the disease and the impossibility of a cure has still been one of the most difficult tasks, if not the most painful for the health professional, due to the possibility of provoking different feelings to the client, as fear of suffering, physical pain and loneliness, contributing to biopsychosocial suffering.⁷

Thus, the discussion about the progress of the disease and preferences about end-of-life care between clients and the multidisciplinary team is necessary to align care with clients’ wishes. And for that to happen, there needs to be a professional-client relationship in which the base is centered on communication.⁸,⁹

It is in this scenario that the Theory of Interpersonal Relations, its concepts and principles support the interpersonal relationships that exist not only in the practice of Nursing, but also of other health professionals who assist the client in palliative care, since, according to the theory, communication therapy is a key point in the relationship between professional and client, in which there is a need to work with the client’s understanding and give him/her a voice in order to make him/her co-participant in the treatment.¹⁰

Therefore, considering the impact that the transition to palliative care can cause, in addition to the increasing demand of this population in health services, it is essential to identify their needs and preferences regarding communication at that moment, so that, together, professionals and clients can improve this communicational process and favor individualized and more humanized care.
Based on the above, the study aims to analyze how the cancer client evaluates communication in the transition to palliative care, identify their needs and preferences about communication in the transition to palliative care related to their prognosis, decision making and family participation and present proposal for facilitating actions for communication in the transition to palliative care, based on the needs and preferences mentioned by the cancer client.

**METHOD**

The research project was submitted to the Ethics Committee of the proposing institution and approved under Opinion Report Nr. 3,137,508 and CAAE 99417418100005285.

It is a qualitative research, outlined based on convergent-care research (CCR). This has as premise the convergence of research actions with that of assistance, aiming to indicate actions for health care, articulating the actions of individuals involved in the context to be researched, in closest relationship of mutual cooperation to integrate theory and practice.12

For this to occur, the research problem must emerge from the care practice in which the results are intended to improve care in the place studied.12 In addition, as a qualitative method, the CCR seeks to identify information that indicates the topic investigated with a view to improvements, which are based on the experiences reported by the research participants, based on the principle of saturation of ideas whose “information from a single subject has the same value, as if coming from all subjects”.12

Having this assertive as a direction, the researcher, who also worked as a nurse in an oncology outpatient clinic, realized the need to know the perspective of the cancer client about communication in the transition to palliative care so that, based on the evidence recognized by him/her, an instrument of facilitating actions for professionals could be developed as a strategy to improve this care, to make the client participate in this process and favor their autonomy in this communication.

For this, the researcher was guided by the Theory of Interpersonal Relations, which understands Nursing as a human relationship experienced between a sick person who needs help and a specialized nurse capable of recognizing and responding to their needs.13 Such relationship becomes it is essential to identify the client’s individuality and make him co-participant in the treatment.13,14 Thus, the use of the guiding theory together with the CCR and its assumptions, especially dialogicity, enabled a dialogical relationship that made it possible to obtain important information about experiences lived by the participants, at the same time that it made possible answers to the needs of the clients that emerged throughout the research.

The study was carried out at the Oncology outpatient clinic of a university hospital in the city of Rio de Janeiro. As an inclusion criterion, it was proposed that clients were undergoing palliative chemotherapy and were over 18 years old. The identification of clients was carried out based on information from the medical record, such as clinical data that confirmed the evolution of the disease, which referred to the description of palliative chemotherapy protocols and terms that referred to palliative care, as well as the psychological approach on the subject through the evolution of Psychology in medical records. As an exclusion criterion, we opted not to approach clients who had difficulty to speak and who had cognitive changes recorded in their medical records. All were selected for convenience, due to their involvement with the research problem. After applying the selection criteria, there was no refusal of those selected or loss of participants during the development of the research, totaling 15 participants at the end.

Data collection took place from January to March 2019. The semi-structured individual interview technique was used, followed by a dialogue with each participant. The dialogue started during the care practice, with the purpose of obtaining information about personal identification, clinical and sociodemographic profile to characterize them. Subsequently, in a reserved room of the Oncology outpatient clinic to ensure the privacy of the participants and with the help of the 10 open-questions script, the dialog discussion with the participants allowed the survey of topics that were the drivers of information, in which the customers were stimulated to the critical reflection of each one.

Each interview lasted an average of 30 minutes, which were audio recorded and later transcribed, respecting the anonymity of each participant, using alphanumeric coding to identify each one. Then, the data were analyzed through thematic analysis, which was developed in three stages: pre-analysis; exploration of the material; treatment of results, inference and interpretation.15 Thus, the data were coded, analyzed and contextualized with the Theory of Interpersonal Relations.

**RESULTS AND DISCUSSION**

The research was composed of 15 cancer patients undergoing palliative chemotherapy. Among the study participants, 53% were male, 47% reported having completed high school, 33% reported being evangelical and 67% reported being married. As for the age group, there was a predominance of the 50-59 years old and 60-69 years old with 33% each. Regarding the diagnosis, 20% had colon cancer and 87% were undergoing palliative chemotherapy in the range 0-1 year, which presupposes aggressiveness and the advanced state of the disease already at the time of hospitalization.

The dialogue between the researcher and the participants started with questions related to the therapeutic path taken up to that moment, previous experiences about communication with professionals and their evaluation, as well as information needs, preferences and how this communication could be improved in the transition for palliative care. After thematic analysis of the speeches,
two thematic subunits stood out: communication in the transition to palliative care: an evaluation of the cancer client; and needs and preferences of the cancer patient in the transition to palliative care.

**Communication in the transition to palliative care: an assessment of the cancer patient**

This subunit was able to portray the cancer client’s view of the communication process that was established with the team before and during the transition to palliative care. This evaluation was important to give the client a voice and understand the negative and positive points cited by them to establish the construction of more customer-centered relationships.

In general, the participants evaluated having obtained good communication with professionals from diagnosis to palliative care, in which welcoming, true and accessible language communication were crucial aspects for an enlightening communication about the moment experienced.

In view of this, it is noted that dialogue is fundamental in human relations, considered a way of humanization that the professional needs to develop in order to empathetically welcome and meet the needs of each individual. During the interview, when asking the client about how he/she would evaluate the information received about the development of his/her disease and current treatment, it was noticed that this dialogic and help relationship often started from a loving and attentive communication.

> It was [...] very friendly, a friendly language, of course with a higher level because I am a doctor, but friendly, a friendly language. [...] they were very affectionate! Cool! Really attentive (E13).

> [...] in this case, I learned a little later, that I did not know the explanation like that in the case of metastasis, you know, I only heard about cancer, cancer [...] it was not for lack of information from them, it was really a lack of knowledge in my case, I heard about it, but I had no understanding, but today it is okay [...] (E11).

> That said, we can see how important and fundamental it is to explain concepts and work with the language that is easy for the recipient, without overestimating him/her, hoping that he/she understands all the terms, but also not underestimating him/her, taking into account the educational level, his/her socio-cultural position and, last but not least, his/her emotional state at that moment.15

Despite the clients evaluating that the language used by the professionals in general was easy and accessible, which facilitated the comprehension and understanding of their current condition and treatment, it was also possible to evidence statements (E11; E14) that highlighted how the use of some technical terms that were not translated into the client’s language resulted in a non-enlightening communication at times.

> [...] in this case, I learned a little later, that I did not know the explanation like that in the case of metastasis, you know, I only heard about cancer, cancer [...] it was not for lack of information from them, it was really a lack of knowledge in my case, I heard about it, but I had no understanding, but today it is okay [...] (E11).

> That said, we can see how important and fundamental it is to explain concepts and work with the language that is easy for the recipient, without overestimating him/her, hoping that he/she understands all the terms, but also not underestimating him/her, taking into account the educational level, his/her socio-cultural position and, last but not least, his/her emotional state at that moment.15

> In view of the participants’ evaluation, it was seen that the relationship of help and good therapeutic communication in the transition to palliative care seems to be related to the team’s ability to...
use verbal language strategies (clear form, colloquial language, sincerity), as well as the non-verbal (smile, affective touch). Only with the use of both forms of language will the team be able to create the necessary bond to meet all the client’s needs and thus obtain quality communication with him/her.

NEEDS AND PREFERENCES OF THE CANCER PATIENT IN THE TRANSITION TO PALLIATIVE CARE

Despite the diverse needs of cancer patients throughout their therapeutic journey, in the transition phase to palliative care the need for information seems to permeate all the others, since this situation is marked by many doubts and uncertainties of what went wrong to arrive up here and what’s yet to come.

Therefore, one of the needs felt by the participants of this research was to obtain more information about the treatment.

My liver is functioning normally. I do not think it should be 100%, but at least 80% I know it is, so why is not there, why can the surgery not be done? [...] So, my question is in this sense, do you understand? [...] Ah, yes, suddenly there will be a need to be treated as a chronic disease, then I ask, does it exist? Understood? My question is this... this I gradually discovered (E12).

It was possible to understand that clients want more information about their treatment, since their doubts so far did not seem to have been completely resolved, perhaps due to the omission of certain information or due to failures in communication that resulted in one not so enlightening until that moment. This may be since communication in palliative care includes emotional and challenging content for all involved, which sometimes results in the omission of some paternalistic information and attitudes by the team. However, the omission of information about the client health does not protect you from emotional or psychological suffering, generating more anguish and difficulty in the adjustment process.18

In this scenario, another need mentioned by the participants during the dialogued discussion was that of more prognostic information.

I want to know how much longer than and if there is another option. It is important to know, I think one must be interested and know exactly what one has, right? (E10).

It was possible to apprehend that clients want to receive prognostic information and that as much as the truth may be painful, they prefer to know everything. This demonstrates how life-threatening diseases, such as cancer at an advanced stage, are associated with high levels of uncertainty that, together with the desire for safety, can manifest themselves through the relentless search for information regarding the diagnosis, treatment and prognosis of life.19

Despite this, the prognostic information is often hesitated by professionals for fear of taking away hope or damaging the relationship and the bond they have achieved, but it is a very desired information by clients, who require increasingly detailed information about their survival, in addition to the benefits and risks of palliative treatments.20,21

Just as the information needs varied according to the degree of interest, lack and individual desires, the preferences about the information were different during the research.

In view of the need for more information about treatment and prognosis, the participants demonstrated the desire to obtain a more active participation in the treatment.

No [...] I would like to participate in the whole process of my treatment, to know everything that is happening, I did the blood test, I did the other tests [...]. “Look, lady, today you are going to stay a little longer because we have to talk about everything that happened here.” At the consultation, right? [...] (E14).

Although the preference for active participation was reported by most participants (73%), a small portion (27%) referred to the preference for passive participation in the treatment. Therefore, the assumption that everyone wants to play an active role in decision-making in the treatment is still very simplistic, given that preferences can change over the course of the disease, in which the preference for more active participation generally occurs as the disease progresses for the final stages.22

Based on this, communication about clients’ wishes and preferences regarding participation in the treatment becomes essential, since they can vary according to the individual needs of each one.

The preference for active participation in treatment characterizes the client’s desire to exercise his/her autonomy in the health-disease process and shapes his/her aspiration to participate in decision-making about the care related to his/her health. This explains the preference for the truth to have been the attribute most required by the participants to meet their needs for prognostic and treatment information.

I prefer to know everything, to know everything that is happening to me [...] Even though the news is not good, because I am aware of everything [...] And I do not like people hiding things from me, I like to know what is going on, so I prefer to know (E2).

It was notable that the truth is configured as a particularly important trait and of good quality in communication for most clients.
(87%). However, a smaller fraction (13%) referred to a predilection for not knowing too much and wanting only the good news.

Although veracity is one of the principles of bioethics that govern palliative care, in which access to information is an important resource in the professional-client relationship that generates trust, it must not be forgotten that it goes far beyond telling the truth, but rather telling the truth to people who want to know the reality of the facts, since good communication should bring benefits to the client and favor the autonomy of their decision-making process and, thus, avoid emotional damage that may be caused by bad news.18,24

In view of this, communication in the transition to palliative care should be centered on the need and desire for information that the client requires, since in some cases not knowing means not suffering and can be a care requested by him/her, thus demonstrating that information about your health is your right, not an obligation, and therefore the desire to not know must also be heard and respected, ensuring the autonomy of not wanting to be informed about bad news.18,23

Another divergence of preferences found in the studied group was in relation to the desire to participate the family about any information related to the disease and the treatment between the client team. In this scenario, a large part of the participants (87%) mentioned favoritism for family participation in the entire communication process, however, different reasons were found, which was something unexpected by the present study.

They have to know, not least because they [...] I think that [...] for them not to be taken by surprise too, for them not to create an expectation that I think is much worse afterwards, so if they follow I think they would be already positioning themselves, I think family members have to know [...] (E12).

Then yes, I prefer to leave it with the family. Because they know it is okay, because if there is something wrong, they will talk, they will go after it. If you must give any news you can give it to them, I prefer not to know lol (E7).

The preference for family participation was found mainly in the group of clients who said they prefer to receive all possible information, both good and bad, and thus involve their family in this communication process so that they can have their support and prepare them for the worst. On the other hand, the same preference was also described by customers who would like to receive only good news and therefore wanted the bad news to be delivered only to the family.

Thus, it was found that the preference for family participation was not uniform, as were the reasons for the desire for family participation. For this reason, discussing values and preferences about whether family members are involved in the dialogues proves to be one of the main aspects to carry out a centralized communication with the client.24

Thus, the divergence of the needs and preferences of the cancer client in the transition to palliative care demonstrates the importance of attentive listening by professionals to carry out a communication centered on the cancer client from diagnosis to palliative care to favor their autonomy throughout the process.

Considering the notes of the participants and the Theory of Interpersonal Relations, facilitating actions for communication in the transition from the cancer client to palliative care were proposed for the field of care practice, which aim to guide health professionals in the communication process at this key moment, according to Table 1.

During the process of dialogued discussion and the questioning of the theme with clients, the demands of each participant arose. They took the opportunity to report uncertainties about the treatment and what they would like to see changed for better communication during consultations with professionals. This made it possible for the researcher/nurse to carry out the necessary guidance on her rights to access information about what was going on, also clarifying the unclear doubts about the stages of treatment. At the same time, it enabled the construction of an instrument with facilitating actions for communication in the transition to palliative care, which was based on the Theory of Interpersonal Relations. Therefore, this process is comprised of four superimposed and interrelated steps, so that the professional can propose care based on the individual’s own conceptions, aiming to offer individualized and co-participative care.14

It is believed that such an instrument is a necessary guide to rescue the focus of care for the sick person. However, its implementation in care practice depends on each professional valuing the interaction and dialogue with the client so that a care plan is built together to meet the specifics of this process, since each client is a unique individual and, therefore, it will be necessary for the professional to evaluate the failures and successes achieved continuously.

**FINAL CONSIDERATIONS**

The study provided the researcher’s intentional approach to care practice, with the objective of obtaining improvements to the place studied with the collaboration of participants of the research, establishing an interpersonal relationship there, which allowed the production of data at the same time as a nurse responded to client needs.

Such relational, dialogic and co-participative process referred to by the theoretical framework as methodological contributed to the development of facilitating actions for communication in the transition to palliative care, based on the needs and preferences identified by the client, in order to facilitate and guide this process towards the team.
In the evaluation of the participants about communication in the transition to palliative care, the welcoming, the attentive way and the information of the truth were essential elements to build a relationship of trust and bond. For this, the simple and accessible language was decisive to establish an enlightening communication about the moment lived. Such aspects demonstrated the value of using verbal and non-verbal strategies to meet the client’s needs. But the clients gave more importance to the way he was informed than to the message itself.

Even so, clients yearned for more information about their treatment and prognosis, which may have come from communication failures at some point or even from an endless search for more information.

Although the majority mentioned the preference for the truth, family participation and active participation in the treatment, others demonstrated the preference for not knowing so as not to suffer from the exclusive participation of the family in access to information, non-family participation and passivity in the participation in the treatment.

Given this, it is possible to say that it will be from the prioritization of active listening actions, welcoming, respect for the client’s autonomy and the use of clear and accessible language that the professional will create the necessary bond and will be more successful in carrying out a communication centered on needs and cancer client preferences.

REFERENCES


