

# Decision making: the role of the speech therapist in palliative care

## Tomada de decisão: papel do fonoaudiólogo em cuidados paliativos

## Toma de decisión: papel del fonoaudiólogo en cuidados paliativos

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### **Abstract**

**Introduction:** Shared decision making is a person-centered strategy, seeking to align communication between health professionals and patients, along with individuals' preferences, values and goals. **Objective:** To correlate the clinical findings of dysarthria, dysphagia and cognition with the health decision-making process of a patient with confirmed molecular diagnosis of Ataxia Telangiectasia, in end-stage palliative care. **Method:** An evaluation of dysarthria, dysphagia and cognition was performed by a speech language pathologist. Based on the results which presented in the evaluation, principles and guidelines of the health decision-making process were addressed, in order to help define the therapeutic process for patients in palliative care. **Results:** The patient presented ataxic dysarthria and moderate to severe oropharyngeal dysphagia. However, despite a significant risk of laryngeal aspiration for all food consistencies, the patient expressed a strong desire to maintain exclusive oral feeding. With regard to cognition, the patient presented normal cognitive functions for his age bracket and education level. Through a process of informed choice and multidisciplinary discussion, and based on principles of shared decision-making in health, we chose to prioritize the patient's desire and to support oral feeding. **Conclusion:** Starting from the shared decision-making process and seeking to minimize the suffering of patients in palliative care, the speech language pathologist must take a new perspective on therapeutic decisions in order to favor and involve the patient and his relatives from the beginning of the diagnosis up to end-of-life decisions.

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### **Authors' contributions:**

LAJS e AA: participated on the study conception, data collection, analysis and interpretation, considerations and decisions about the study methodology, writing of the article; MRO: participated on the study conception, data collection, analysis and interpretation, considerations and decisions about the study methodology, revisal of the manuscript writing, final revision.

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### Resumo

**Introdução:** A tomada de decisão compartilhada é uma estratégia centrada na pessoa, procurando alinhar a comunicação entre profissionais da saúde e pacientes, conjuntamente com as preferências, valores e objetivos dos indivíduos. **Objetivo:** Correlacionar os achados clínicos da disartria, disfagia e cognição com o processo de tomada de decisão em saúde em um paciente com diagnóstico molecular confirmado de Ataxia Telangiectasia em cuidados paliativos em fase terminal. **Método:** Foi realizada avaliação clínica fonoaudiológica da disartria, disfagia e cognição. À partir dos resultados apresentados na avaliação, foram abordados princípios e diretrizes do processo de tomada de decisão em saúde, a fim de auxiliar na definição do processo terapêutico em pacientes em cuidados paliativos. **Resultados:** Paciente apresentou disartria atáxica e disfagia orofaríngea moderada a grave, porém apesar do risco significativo de aspiração laríngea para todas as consistências alimentares, demonstrou forte desejo em manter alimentação via oral exclusiva. Com relação à cognição paciente apresentou funções cognitivas de acordo com a normalidade para idade e escolaridade. Por meio de um processo de escolha informada, discussão multidisciplinar e baseando-se em princípios da tomada de decisão compartilhada em saúde, optou-se por priorizar o desejo do paciente e indicou-se alimentação via oral. **Conclusão:** Partindo do processo de tomada de decisão compartilhada e buscando minimizar o sofrimento de pacientes em cuidados paliativos, o fonoaudiólogo deve assumir uma nova perspectiva às decisões terapêuticas a fim de favorecer e envolver o paciente e seus familiares desde o início do diagnóstico até as decisões de fim de vida.

**Palavras-chave:** Cuidados paliativos; Tomada de decisões; Qualidade de vida; Fonoaudiologia; Transtornos de deglutição.

### Resumen

**Introduction:** La toma de decisiones compartida es una estrategia centrada en la persona, buscando alinear la comunicación entre profesionales de la salud y pacientes, junto con las preferencias, valores y objetivos de los individuos. **Objetivo:** Correlacionar los hallazgos clínicos de la disartria, disfagia y cognición con el proceso de toma de decisión en salud en un paciente con diagnóstico molecular confirmado de Ataxia Telangiectasia en cuidados paliativos en fase terminal. **Método:** Se realizó una evaluación clínica fonoaudiológica de la disartria, disfagia y cognición. A partir de los resultados presentados en la evaluación se abordaron principios y directrices del proceso de toma de decisión en salud, a fin de auxiliar en la definición del proceso terapéutico en pacientes en cuidados paliativos. **Resultados:** Paciente presentó disartria atáxica y disfagia orofaríngea moderada a grave, pero a pesar del riesgo significativo de aspiración laríngea para todas las consistencias alimenticias, demostró fuerte deseo en mantener alimentación oral exclusiva. Con respecto a la cognición paciente presentó funciones cognitivas de acuerdo con la normalidad para edad y escolaridad. Por medio de un proceso de elección informada, discusión multidisciplinaria y basándose en principios de la toma de decisión compartida en salud, se optó por priorizar el deseo del paciente y se indicó alimentación oral. **Conclusión:** Partiendo del proceso de toma de decisión compartida y buscando minimizar el sufrimiento de pacientes en cuidados paliativos, el fonoaudiólogo debe asumir una nueva perspectiva a las decisiones terapéuticas a fin de favorecer e involucrar al paciente ya sus familiares desde el inicio del diagnóstico hasta las decisiones de fin de vida.

**Palabras claves:** Cuidados paliativos; Tomada de decisiones; Calidad de vida; Fonoaudiología; Trastornos de deglución.

## Introduction

Ataxia telangiectasia (AT) is an autosomal recessive disease mainly associated with mutations in the ATM gene<sup>1</sup>. Patient phenotype may vary depending on the mutation in the ATM gene, but all cases present cerebellar degeneration, telangiectasia, immunodeficiency, cancer susceptibility, and radiation sensitivity. Other abnormalities also include gonadal atrophy, delayed pubertal development and insulin-resistant diabetes. With the exception of consanguineous populations, people of all races and ethnicities are equally affected by AT and their worldwide prevalence is estimated to be between 1 - 9/100000 births<sup>2</sup>.

Pulmonary diseases are common in patients with AT and often worsen with age and neurological decline. Recurrent sinopulmonary infections accompanied by bronchiectasis, interstitial lung disease and other lung conditions, may result from repeated episodes of aspiration due to neurogenic swallowing problems - otherwise known as neurogenic dysphagia<sup>3</sup>. This symptom, in turn, is common in AT and usually appears during the second decade of life due to changes in the coordination of the phono-articulatory organs necessary for efficient swallowing<sup>4</sup>. Even though dysphagia may be more easily perceived in AT patients upon the ingestion of thin liquids, they may actually present aspiration risks for all food consistencies. As the disease progresses, they may eventually require alternative feeding methods<sup>5</sup>.

In addition to dysphagia, studies have reported the symptom of dysarthria in children with AT, characterized by oral motor dysfunction and different degrees of intellectual disability, together with deficits in attention, nonverbal memory and verbal fluency<sup>6</sup>.

According to the World Health Organization (WHO), palliative care is an approach that improves the quality of life of patients who face problems associated with terminal disease through the prevention and relief of suffering. It rests on the strategies of early detection, proper assessment and the appropriate treatment of pain and other physical, psychological and spiritual needs. Moreover, palliative care is no longer restricted to the final stage of a disease; rather, it can begin from the moment a degenerative disease or a disease with no cure is diagnosed<sup>7</sup>.

The study of decision-making began in the economic and accounting sciences and referred to a choice made after considering two or more possibilities<sup>8</sup>. Nowadays, the multiple options available within the sphere of patient management often give rise to challenging decision-making processes and perhaps even opposing views. The level of uncertainty is that much higher when a professional is confronted with high-risk choices that entail potential gains or significant losses for the patient<sup>9</sup>.

Based on this, in this article we discuss the shared decision making process which underpinned therapeutic planning for one patient with AT. Through this approach, we sought to align communication between health professionals and patients, together with individual preferences, values and objectives<sup>10</sup>. This process depends heavily not just on an exchange of information, but also the joint construction of consensus to culminate in the best treatment choice for each case. Although the concept of palliative care is widely discussed within the oncological community, the same topic is still relatively incipient when it comes to neurological and young patients. The subject of our study was a young adult at the end stage of AT, whose condition had been previously confirmed through molecular diagnosis. From this case, we aim to correlate the clinical findings of dysarthria, dysphagia, and cognition with our process of decision-making regarding his palliative health care

## Method

The subject was a 21-year-old male patient who had completed 14 years of formal education and was a university student at the time of intervention. He had received a confirmed molecular diagnosis of AT upon the onset of symptoms at 2 years of age. He had been a wheelchair user since the age of 10. He was dependent on his family for his daily care and living activities. When he arrived for his first speech-language assessment, he informed our team that he was still fed orally and described a personal history which included recurrent bronchopneumonia (BCP) - he had been admitted to hospital three times in the previous 6 months in order to treat BCP - and weight loss.

## Speech-Language Pathology

The following self-perception protocols for dysphagia and dysarthria were applied:

The Eating-Assessment Tool (EAT-10)<sup>11</sup>: This questionnaire is a self-assessment tool aimed at identifying risk for dysphagia. It is composed of ten simple questions which provide information about the functionality, emotional impact, and physical symptoms of a swallowing problem. The maximum score is 40 points. Patients who score  $\leq 3$  points are considered to be at risk for dysphagia. Our subject's score was 15 points.

The Radboud Oral Motor Inventory for Parkinson's disease (ROMP) Questionnaire<sup>12</sup>: This is also a self-assessment tool which targets three domains: speech (7 items), swallowing (7 items) and saliva (7 items). Patients are asked to respond on a scale ranging from 1 to 5 points (where one is considered normal and five is the worst score). Our patient's scores were 16, 21 and 14, respectively.

A clinical evaluation of swallowing was also performed, using the Northwestern Dysphagia Patient Check Sheet (NDPCS)<sup>13</sup>. Patients are assessed according to a checklist of 28 clinical signs and symptoms. The higher the score, the greater the severity of dysphagia. This particular patient received a total of 20 points (including recurrent pneumonia, aspiration pneumonia, intermittent fever, poor ability to handle oral secretions, poor posture control, fatigue, swallowing apraxia (except when following verbal commands) and problems swallowing saliva and other food consistencies safely).

Finally, an objective evaluation of swallowing was performed by videofluoroscopy, after which the patient score 8 on the Rosenbeck et al., 1996, and received a diagnosis of moderate to severe oropharyngeal dysphagia (O'Neil, 1999)<sup>14</sup>. On the Functional Scale of Oral Ingestion (FOIS), he was given a score of 2, which corresponds to a patient who is dependent on an alternative method of feeding for nutritional purposes but may be given minimal amounts of food or liquid by mouth<sup>15</sup>. In addition, during this test, he was found to be aspirating saliva, thin liquids and pureed food. Manoeuvres such as the chin tuck, multiple swallows, coughing, and throat clearing followed by swallowing were all tested. None were found to be beneficial in adequately protecting the upper airway. During the clinical assessment, the patient presented vital signs with baseline readings of SpO<sub>2</sub> 93% and a heart rate of 150 bpm.

For the clinical evaluation of dysarthria, the five speech subsystems were assessed: respiration, phonation, resonance, articulation and prosody.

We observed articulatory imprecision, distortions in consonant and vowel sounds, and a decrease in speech velocity; what is more, intelligibility was significantly impaired. Based on his performance, he was diagnosed as having ataxic dysarthria<sup>16</sup>. Nevertheless, although the patient's intelligibility had been affected, the functionality of his communication was partially maintained, making it possible for him to respond verbally to self-report questionnaires.

Cognitive screening tests (the Mini-Mental State Examination<sup>17</sup> and the Montreal Cognitive Assessment<sup>18</sup>) were also carried out. The patient's cognitive functions were found to be normal according to the parameters of age range and the number of years of formal education.

After our speech-language assessment, the case was discussed with the medical and nutritional staff, as well as the patient and his family. With regard to alternative methods of nutrition because of his oropharyngeal dysphagia, there was a general consensus that, due to the fact that the disease had already progressed considerably, the patient's clinical condition did not make him a good candidate for gastrostomy insertion. Nasogastric catheter feeding was another option that was considered; however, the team concluded that this too would have been a very invasive procedure that would not have provided any quality-of-life benefits at the time. There was the further matter of aspirating saliva. Even with oral feeding restrictions, the patient undoubtedly continues to aspirate saliva. As such, the related risk of respiratory tract infection (and other sequelae) could no longer be completely avoided. The patient's wish to maintain an active social life and an oral diet was also taken under consideration. Ultimately, a group decision was made to continue to support an oral, pureed diet enriched with the appropriate nutritional supplements.

One week later, the patient reported that he would not follow the healthcare team's recommendations concerning food consistency restrictions. He had decided to enjoy a regular diet, regardless of the grave respiratory risks posed.

Over the course of intervention, joint decision making was carried out in five meetings with an average duration of 45 minutes each. At the first visit, only the speech language pathologist was present in room with the patient and his mother. The risks of continuing an oral diet were discussed. The case doctor as well as a nutritionist was also

present for the second and third visits. In this multidisciplinary format, an attempt was made to explore clinical risks and possibilities with a view to adapting therapy and treatment to the patient's wishes. Only the patient's mother came to the speech language pathology outpatient clinic for the last two visits because the clinical condition of her son had worsened. She acknowledged the terminal status of the patient and reaffirmed her support of his decisions regarding quality of life, in spite of the risks. All visits and decisions were registered in the electronic medical record system of the hospital. The patient died within 15 days after the last outpatient visit.

### *Ethical issues*

This project was approved by the hospital's Ethics Committee under number 2018-0323. Both patient and caregiver signed the relevant consent forms.

## **Results and discussion**

Shared decision-making depends on building a good patient-healthcare team relationship so that information is shared and patients receive support to think about treatment options and express their preferences and opinions<sup>10</sup>. This process involves an ethical question intertwined with the interpersonal relationship, which can serve as a filter for decision making. A health professional should use all his knowledge and concern for the welfare of the patient, their family and the wider community to highlight all the pros and cons of each treatment option. Then, together with the patient and other professionals involved in case, decide on the best choice<sup>19</sup>. Based on this perspective, decisions and actions in the above-mentioned case were centered on patient well-being, and took into account the values and principles that guided him and his family members.

Published research has shown the need for effective communication in order to respect the patient's right to informed choices<sup>20,21</sup>. Thus, the presentation of adequate information, a willingness to reflect and adapt and the use of contributory technique are important elements in patient education<sup>21</sup>. For this to occur, healthcare professionals must not only master technical knowledge so as to avoid making intuitive decisions, but also ally knowl-

edge with experience. These professionals can and should influence how information is understood.

In the context of palliative care, it is indispensable to involve and incorporate a continuity of care, effective management of the chronic palliative interface and a multidisciplinary network of professionals who work actively involving patients and caregivers since diagnosis.

However, such an approach may seem to run counter to the debate about end-of-life decisions and how to die. Nowadays, there has been considerable reflection on the idea that doing everything possible to extend a patient's life is not always appropriate or desirable. However, because our attention is usually focused on the disease, in many cases the patient is treated as a passive and uninformed recipient rather than as an autonomous human being who has sovereignty over all health and end-of-life decisions. It is still not uncommon to observe this right being ignored<sup>22</sup>.

In the case presented in this article, the patient and his caregiver expressed distress when they thought about ceasing oral feeding. All information was provided regarding the risks of maintaining oral feeding (respiratory tract infection and associated clinical decline), as well as the benefits (quality of life and oral pleasure for critical patients with low life expectancy). Establishing effective communication between all parties was a clear priority, with the perception and understanding that what was being said was essential.

According to Tversky and Fox<sup>23</sup>, this type of decision is defined as a risk decision, since probability is analyzed with results. As for the healthcare team involved in our case, composed of other health professionals with experience in neurodegenerative diseases, decision-making was based on a descriptive approach, in which the rationale and gross results of the exams were not the only factors taken into account. In this situation, a solution that was "good enough" for the patient at that point of his life and decline was the most appropriate choice.

It is worth mentioning that, like this case, healthcare decision-making is often centered on the essence of what is being discussed. At no time does this kind of reflection attempt to place a general rule over the management of patients in terminal palliative care. Rather, it is meant as a guideline for a unique way of seeing a patient in the midst of numbers, proportions, results, exam objectives and

risks. The definition of contemporary therapeutic conduct, besides being interdisciplinary, must also include the individual, cultural, historical, values and principles of each patient

### Final considerations

It is up to health professionals like speech language therapists to give a new face to therapeutic decision making, starting with the principles of shared decision making and informed patient choice. In this manner the concept of quality of life, which is so frequently discussed in the realm of palliative care, can be better incorporated into the options that patients and their families choose along their life journey.

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