

ANALYSIS OF THE QUALITY OF LIFE OF PROFESSIONALS WORKING IN HOME CARE

Análise da qualidade de vida de profissionais que atuam na atenção domiciliar

Análisis de la calidad de vida de profesionales que actúan en la atención domiciliar

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ABSTRACT

Objective: This study aimed to evaluate the quality of life of the professionals working in an Interdisciplinary Oncology Home Intervention Program. **Method:** This is an exploratory descriptive study with a quantitative approach, in which the sample was composed of 19 professionals who carry out home visits. A self-administered questionnaire containing sociodemographic data and The World Health Organization Quality of Life (WHOQOL - 100) was used. Socio - demographic data were analyzed using IBM SPSS Statistics 20 and WHOQOL 100 through Microsoft Excel. **Results:** The domain that presented the lowest score was the physical domain (55%), followed by the psychological domain (62%), environment (63%), independence level (74%) and spiritual / religion / personal beliefs). Regarding the quality of life from the point of view of the evaluated, we obtained a score of 66%. **Conclusion:** Based on the results obtained, it is fundamental to increase the actions focused on quality of life, as well as new researches in the area.

Descriptors: Palliative care; Home care; Quality of life.

RESUMO

Objetivo: Este estudo buscou avaliar a qualidade de vida dos profissionais atuantes em um Programa de Internação Domiciliar Interdisciplinar Oncológico. **Método:** Trata-se de um estudo descritivo exploratório de abordagem quantitativa, na qual a amostra foi composta por 19 profissionais que realizam visitas domiciliares. Foi utilizado um questionário autoaplicável contendo dados sociodemográficos e o *The World Health Organization Quality of Life (WHOQOL - 100)*. Os dados sociodemográficos foram analisados através do *IBM SPSS Statistics 20* e o *WHOQOL 100* através do *Microsoft Excel*. **Resultados:** O domínio que apresentou escore mais baixo foi o domínio físico (55%), seguido do psicológico (62%), ambiente (63%), nível de independência (74%) e aspectos espirituais/religião/crenças pessoais (74%). Com relação à qualidade de vida do ponto de vista do avaliado, obteve-se um escore de 66%. **Conclusão:** A partir dos resultados obtidos, torna-se fundamental a ampliação das ações voltadas à qualidade de vida, bem como novas pesquisas na área.

Descritores: Cuidados paliativos; Atenção domiciliar; Qualidade de vida.

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RESUMEN

Objetivo: Este estudio buscó evaluar la calidad de vida de los profesionales actuantes en un Programa de Internación Domiciliar Interdisciplinario Oncológico. **Método:** Se trata de un estudio descriptivo exploratorio de abordaje cuantitativo, en el cual la muestra fue compuesta por 19 profesionales que realizan visitas domiciliarias. Se utilizó un cuestionario autoaplicable que contenía datos sociodemográficos y The World Health Organization Quality of Life (WHOQOL - 100). Los datos sociodemográficos se analizaron a través de IBM SPSS Statistics 20 y el WHOQOL 100 a través de Microsoft Excel. **Resultados:** El dominio que presentó una puntuación más baja fue el dominio físico (55%), seguido del psicológico (62%), ambiente (63%), nivel de independencia (74%) y aspectos espirituales / religión / creencias personales (74%). Con respecto a la calidad de vida desde el punto de vista del evaluado obtuvimos una puntuación del 66%. **Conclusión:** A partir de los resultados obtenidos se torna fundamental la ampliación de las acciones volcadas a la calidad de vida, así como nuevas investigaciones en el área.

Descritores: Cuidados paliativos; Atención domiciliaria; Calidad de vida.

INTRODUCTION

The diagnosis of cancer affects the individual and their family in view of its complexity and the stigma related to this disease. The diagnosis causes in individuals and family members a change in routine due to the need to perform procedures aimed at healing, maintenance and/or improvement of quality of life, as well as the need to move to a neighboring municipality, when the place of origin does not have this type of treatment.¹

In addition to the change in routine, a mixture of feelings occurs after the diagnosis, such as sadness, fear of death, as well as hope in carrying out the treatment and getting a “positive result”, which would be the cure of the disease.¹⁻² Regarding treatment, there are several procedures involved, ranging from chemotherapy, radiotherapy and surgery, which can cause adverse effects to the patient.

In all stages of treatment, the health professional has a fundamental role in the care of the oncological patient and their family, both assisting in the clinical part and also demonstrating empathy, making the patient and family members feel welcomed in all stages of care.

Law No. 10,424, of April 15, 2002, guaranteed an expansion of health care including home care and home hospitalization within the Unified Health System (SUS), providing individuals with comprehensive care in the comfort of their home. This modality of care includes care by a multiprofessional team (doctors, nurses, social workers, physiotherapists, psychologists, occupational therapists, among others) from a preventive, therapeutic and rehabilitative perspective. In order for there to be this type of care, medical designation is required, as well as the patient and family members' agreement on the matter.³

Ordinance No. 825, of April 25, 2016, redefines home care within the SUS emphasizing the care parameters, as well as the definition of teams aiming to provide a multidisciplinary

and integral care to patients, classifying and referring them to the respective teams according to the clinical needs of each individual.⁴

In this perspective, the School Hospital of the Federal University of Pelotas, as a reference in oncological care in the southern region of the state of Rio Grande do Sul, offers, since 2005, the Interdisciplinary Oncology Home Hospitalization Program (PIDI). This program consists of interdisciplinary home visits twice a day, regardless of the stage of the disease. The intervention is aimed at the treatment of complications related to oncological treatment (chemotherapy or radiotherapy), as well as for the management of signs and symptoms of those patients who find themselves with the disease in an advanced stage, without the possibility of cure. PIDI also offers assistance to caregivers and mourners.⁵

The interdisciplinary team consists of a reference team (doctor, nurse, nursing technician and social worker) and a support team (psychologist, occupational therapist, dentist, nutritionist, spiritual counselor, physiotherapist). These professionals meet weekly to discuss clinical cases and unique therapeutic planning.⁵

It is important to emphasize that many oncological patients may not present any more possibilities of cure, which makes it essential, from the perspective of integral care to the patient and family, to act based on the philosophy of palliative care. In this sense, the search for promotion of the quality of life of patients and family members and the relief of total pain (physical, psychological, spiritual and social) are the focus of the team's care. By attending to this perspective, death is faced as a natural process, which should not be postponed or anticipated, and all assistance remains until the caregivers/family members' mourning period.⁶⁻⁸

According to Oliveira, Souza, Bushatsky, Damaso, Bezerra and Brito⁹, as the last days of life approach, the need for palliative care increases, being essential an integration between the caregiver and the health team, seeking to offer quality of life to the patient until the end of life. In this sense, PIDI is able to provide comprehensive care to the patient and family, due to actions that are planned and developed according to the principles of palliative care.

Dealing with palliative care patients who, in many cases, are already in the final stage of life can be difficult for the health professional, since oncology is considered an area that causes great stress in these individuals, considering the care that needs to be offered, which is not restricted only to the patient, but also extends to the family.¹⁰

Being agents of care, these professionals need to be well to bear the physical and emotional burden imposed by the work, because acting in the health area, specifically with cancer patients, requires the professional to deal with the suffering of others and death.¹¹ In this sense, this study aimed to evaluate the quality of life of professionals working in an Interdisciplinary Oncology Home Hospitalization Program.

METHOD

This is an exploratory descriptive study with a quantitative approach that aims to analyze the quality of life of professionals working in home care for cancer patients in a reference hospital in Oncology in the city of Pelotas, southern region of Rio Grande do Sul, Brazil.

All PIDI professionals who work directly with the patients at home, including reference teams and support teams, were invited to participate in the study. Residents who act in this scenario were also invited to participate.

The inclusion criteria were: accepting to participate in the research voluntarily; being a health professional of the team of the Interdisciplinary Oncology Home Hospitalization Program (PIDI) of the Teaching Hospital of the Federal University of Pelotas, including residents; acting in home care in the minimum period of three months. Exclusion criteria: not being active during the data collection period; presenting incomplete questionnaire, making it impossible to calculate the domains.

A self-administered questionnaire was used as an instrument for data collection to obtain sociodemographic data and information regarding age, sex, marital status, level of education, profession, length of employment, religion, weekly workload and other work activities performed. The *WHOQOL-100* quality of life questionnaire (Portuguese version) was also applied, created by the World Health Organization, which presents 100 items divided into 6 domains (physical, psychological, level of independence, social relations, environment and spiritual aspects/religion/personal beliefs), 24 facets and a general domain on quality of life in the participant's perception. This instrument does not demonstrate normative data for Brazil, for this it would be necessary to perform a local control group to compare the results. However, it is assumed that the closer to the total value 100, the better the individual's quality of life is considered.¹²

The professionals were approached in their workplace and some chose to take the questionnaire home, turning it in later. The collection was carried out in January and February 2019. Of the 25 professionals who act directly in the care performing regular home visits, three were away from work activities, one did not fit the inclusion criteria, and one of the professionals is the researcher. The others agreed to participate in the study (n = 20). However, a questionnaire was discarded because it presented incomplete questions that would make it impossible to analyze some domains of the *WHOQOL-100* questionnaire.

The sociodemographic data were analyzed using the IBM SPSS statistical program version 23.020 and the *WHOQOL-100* data using *Microsoft Excel*.

For the development of this research, all the ethical measures provided for in CNS Resolution No. 466 of December 12, 2012 were taken. The research was submitted to the Brazil platform and approved by the Ethics Committee of the Faculty of Medicine of the Federal University of Pelotas (UFPEL - Comitê de Ética da Faculdade de Medicina da Universidade Federal de Pelotas) on 21/12/2018 and received the number CAAE 04710818.6.0000.5317. All participants signed the informed consent form.

RESULTS AND DISCUSSION

Regarding the characterization of the sample, the female gender was predominant, with 63.2% (n=12), and the age range of the sample ranged from 25 to 65 years old, with a mean age of 39 years old. Regarding marital status, the majority of the sample was divided between single 36.8% (n=seven) and married 31.6% (n=six). Most of the sample reported having one or more children 57.9% (n=11). Regarding education, 52.9% (n=10) reported having at least a degree, some with specialization in progress, as is the case of residents. Of the 19 participants, 21.1% (n=four) were residents, 36.8% (n=seven) have some postgraduate studies and 10.5% (n=two) have a master's degree. The study sample consisted of physicians 15.8% (n=three), nurses 21.1% (n=four, being one a resident), nursing technicians 21.1% (n=four), psychologist 5.3% (n=one resident), dentist 10.5% (n=two residents), occupational therapist 5.3% (n=one), physiotherapist 10.5% (n=two), nutritionist 5.3% (n=one) and social worker 5.3% (n=one). The period of service varied from 6 to 156 months, with an average time of 53.7 months, that is, approximately 5 years. In this item, it should be taken into account that many of the professionals working in PIDI already worked in home care in the Best at Home Program (Programa Melhor em Casa), thus reflecting on the long period of some in this service, which raised the average. The weekly workload varied between 4 and 44 hours, and most of the sample 68.42% (n=13) worked between 30 and 40 hours per week. It is important to note that many of these professionals perform activities in other spaces in the hospital network that they work for, not being exclusive to PIDI. Only 31.6% (n=six) perform another paid activity and 73.7% (n=14) declared having some religion, with predominance of the Catholic 26.3% (n=five) and Spiritist 26.3% (n=five) religions.

Regarding the *WHOQOL-100* data, the studied population presented a perception of quality of life around 66%. When analyzing the quality of life and health by domains, it was observed that the domains related to the level of independence and spiritual aspects/religion/beliefs were those that presented scores greater than 70% (Figure 1). The result by facets is described in Figure 2.

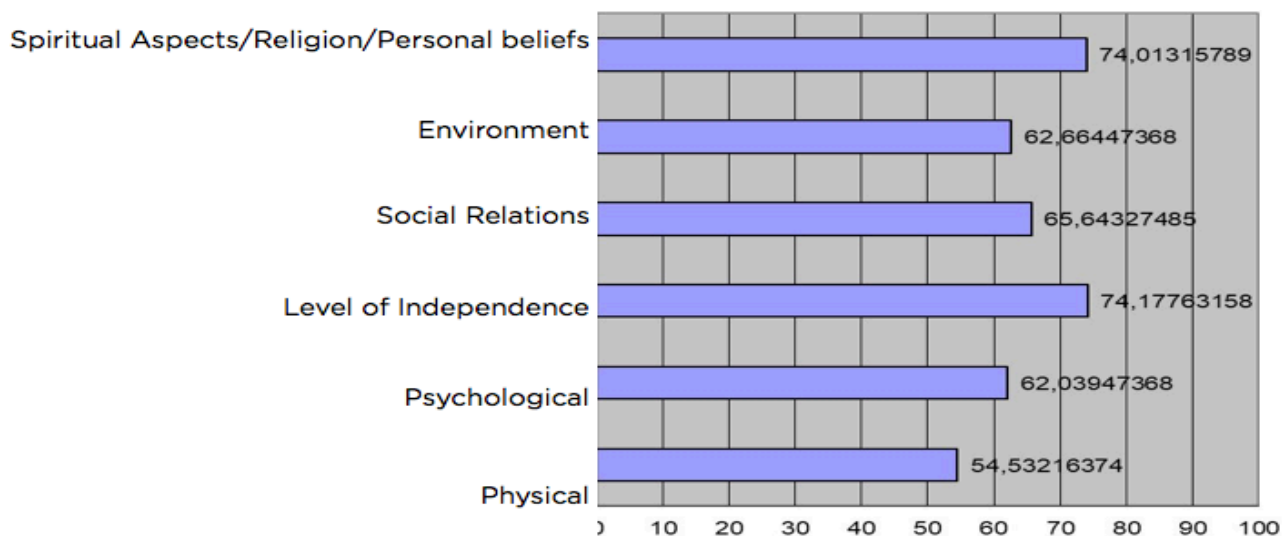
Table 1 - Characterization of the population

RESIDENT		
Yes	4	21.10%
No	15	78.90%
AGE		
25-35	9	47.37%
36-50	7	36.84%
>50	3	15.79%
SEX		
Female	12	63.20%
Male	7	36.80%
MARITAL STATUS		
Single	7	36.80%
Married	6	31.60%
Divorced	4	21.10%
Other	2	10.50%
CHILDREN		
None	8	42.10%
One	5	26.30%
Two	5	26.30%
Three or more	1	5.30%
LEVEL OF EDUCATION		
Graduation	10	52.60%
Postgraduation studies	7	36.80%
Masters	2	10.50%
PROFESSION		
Physician	3	15.80%
Nurse	4	21.10%
Dentist	2	10.50%

Psychologist	1	5.30%
Nursing technician	4	21.10%
Nutritionist	1	5.30%
Occupational therapist	1	5.30%
Social worker	1	5.30%
Physiotherapist	2	10.50%
OPERATING TIME (MONTHS)		
6 - 24	7	36.84%
25 - 36	4	21.05%
37 - 80	3	15.79%
> 80	5	26.32%
WEEKLY WORKLOAD		
< 30 hours	5	26.32%
30 - 40 hours	13	68.42%
> 40 hours	1	5.26%
ANY OTHER PAID ACTIVITY		
Yes	6	31.60%
No	13	68.40%
RELIGION		
Catholic	5	26.30%
Evangelic	1	5.30%
Umbandist	2	10.50%
Spiritist	5	26.30%
Other	1	5.30%
None	5	26.30%
TOTAL	19	100%

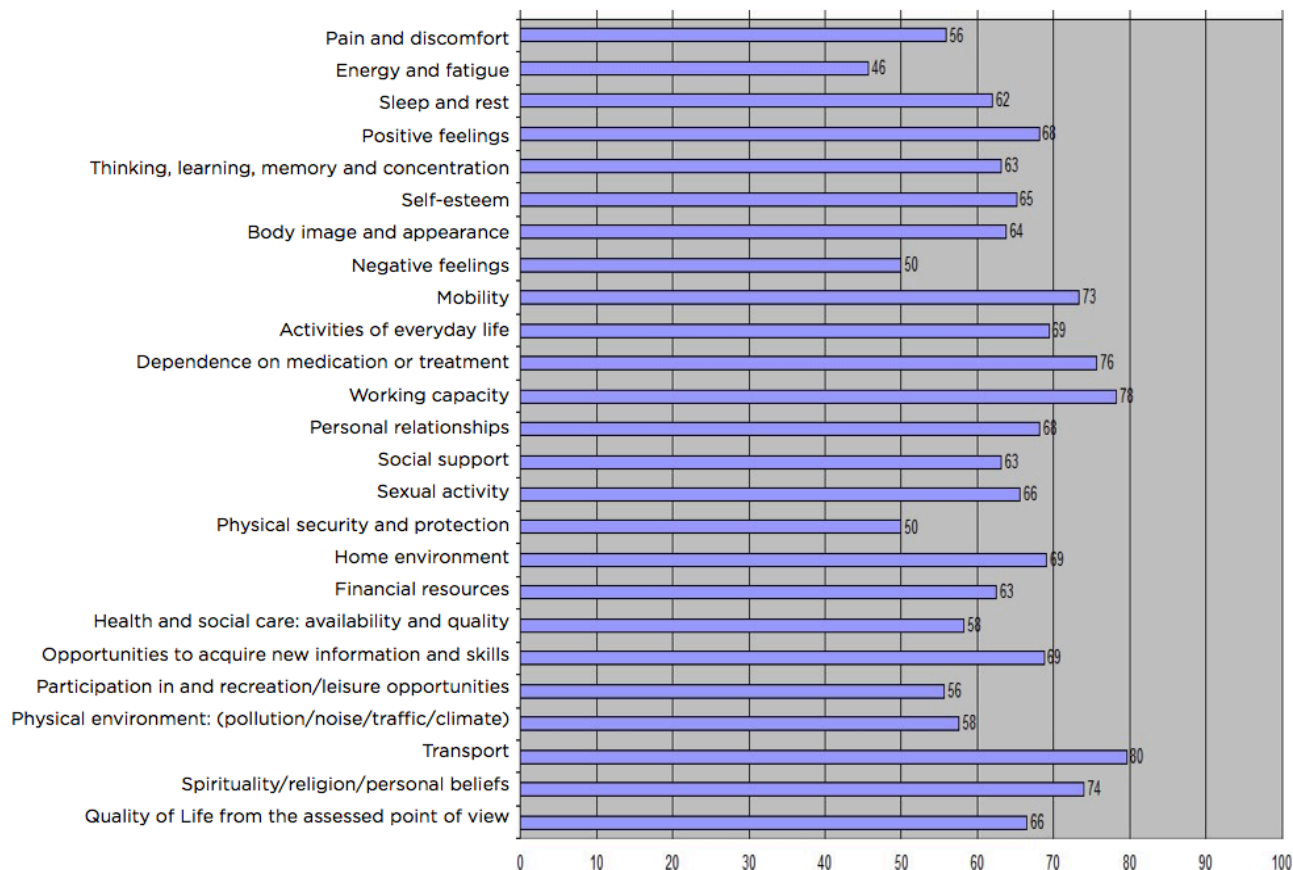
Source: Research, 2019.

Figure 1 - WHOQOL-100 domains.



Source: Research, 2019.

Figure 2 - Facets of WHOQOL-100 domais.



Source: Research, 2019.

The domains that presented the best scores were those related to “level of independence” and “spiritual aspects/religion/personal beliefs”. In the first domain, the corresponding facets referred to “mobility” (73%), “daily life activities” (69%), “dependence on medication or treatment” (76%) and “working capacity” (78%). It is observed that these professionals presented a good level of independence and that they consider that they can perform work activities. Fernandez, Miranzi, Iwamoto, Tavares and Santos¹³ presented, in their research with nurses of the Family Health Strategy, a similar score in this domain. However, there is a shortage of Brazilian studies using the *WHOQOL-100* instrument aimed at the studied population, which makes it difficult to exploit data with national references.

In the domain related to “spiritual aspects/religion/personal beliefs”, it is observed in the facet about “spirituality/religion/personal beliefs” that the score obtained was 74%. This domain evaluates a person’s personal beliefs, independent of a specific religion, thus analyzing the influence on the interviewee’s quality of life. La Longuiniere, Yarid, and Silva¹⁴, in their research on the influence of religiosity/spirituality of health professionals in the care of critical patients, report the importance of experiencing spirituality for the quality of life of professionals, as well as for their physical health and improvement of interpersonal relationships. The experience of spirituality can increase the quality of life, since beliefs can modify the way each professional understands disease and terminality.

The “social relationships” that include the facets related to “social support” (63%), “personal relationships” (68%) and “sexual activity” (66%) showed no significant changes between the facets. Porto, Thofehrn, Pai, Amestoy, Arrieira and Joner¹⁵, based on their research on the vision of PIDI professionals about their performance in the program, demonstrated the importance of interpersonal relationships in the work environment, being used as a tool to cope with adverse situations experienced in this environment. The score of this domain corroborates with the data obtained related to the previously discussed facet, in which, based on what was presented by La Longuiniere, Yarid, and Silva¹⁴ and Porto, Thofehrn, Pai, Amestoy, Arrieira and Joner¹⁵, it is understood the importance to provide support to professionals to deal with patients in palliative care.

In the psychological domain, it can be observed that the corresponding facets were presented to the following values: “positive feelings” (68%), “thinking, learning, memory, and concentration” (63%), “self-esteem” (65%), “body image and appearance” (64%) and “negative feelings” (50%). The latter, according to its concept in the manual of *WHOQOL-100*, refers to how distressing are negative feelings experienced and the impact on the daily lives of individuals.¹² In this sense, one can reflect on the origin of these negative feelings, which may be related to professional practice since they deal daily with the suffering of cancer patients and their families, as well as related to their personal lives.¹¹ It is necessary to reflect that even though they are agents of care, these professionals are

not unharmed to situations of suffering in their lives, and can thus experience the process of illness with loved ones, as well as suffering from other sources. Thus, it is impossible to make a direct correlation of the score of this facet and its connection with work activities.

In the domain “environment”, the aspects that presented a lower score were related to the “physical safety and protection” (50%), “health and social care: availability and quality” (58%), “participation in and opportunities for recreation and leisure activities” (56%) and “physical environment (pollution, noise, traffic, climate)” (58%). Due to the weekly workload that most professionals (between 30 and 40 hours a week) perform, as well as performing other activities besides work, the facet “participation in and opportunity for recreation and leisure” makes us reflect on how professionals have organized their time, what are the occupations that they have prioritized in their free time, what they understand about leisure and its importance.

Leisure can be understood as an unnecessary occupation or associated with a high financial cost. However, like other occupations (activities of daily life, instrumental activities of daily life, rest and sleep, work, education), it has an important role in the life of the individual, enabling the promotion of autonomy and, consequently, personal achievement, since it is related to the performance of significant activities.¹⁶

Regarding the facets related to “physical safety and protection” and “physical environment” we can reflect on what physical resources the work space offers to promote quality of life at work, as well as the strategies used to promote the safety of professionals who daily visit patients in several neighborhoods of the city.¹⁷

Among all domains, the lowest score was the “physical” domain. Among its facets, the one with the lowest score was related to “energy and fatigue” (46%), followed by “pain and discomfort” (56%) and “sleep and rest” (62%). This shows that even if the professional does not work in the physical part of the hospital, when working in the patient’s home, they also present impairments to physical health when performing procedures that require some physical effort, as well as the dynamics of home visits with different addresses, exposure to climatic conditions and other factors. The results obtained in the “physical” and “environmental” domains are similar to those found by Souza, Silva, Lima, Teston, Benedetti and Costa¹⁷, which identified impairment in the quality of life of professionals working in critical sectors of the hospital.

The *WHOQOL 100* instrument (Portuguese version) does not demonstrate normative data for Brazil, for this it would be necessary to perform a control group to compare the results.¹² However, from the understanding that the closer to the total value 100, the better the quality of life of the individual is considered, it can be observed that the score related to quality of life from the point of view of the evaluated was 66%, thus demonstrating that there are factors that need to be improved. However, the limitation in this study is the impossibility of directly correlating the lower scores with work activity, as well as the scarcity of similar studies for comparison.

CONCLUSION

According to the results obtained in this study, it was observed that the participants considered to have a good ability to perform the activities that are required daily, including mobility and work activity. Another domain that presented a good score was related to spiritual aspects/religion/personal beliefs, demonstrating that, even participants who have not declared having any religion, the experience of spirituality somehow reflects on their quality of life.

Even demonstrating higher scores in these domains, it is important to emphasize that professionals working in the field of Oncology in home care demonstrated impairments in some areas of the test domain, the lowest score being related to the physical domain. Regarding the facets, those with lower scores refer to energy and fatigue (physical domain), negative feelings (psychological domain) and safety and protection (environment domain). Therefore, a sensitive look at the results obtained and the expansion of actions aimed at promoting the quality of life of professionals is essential.

Limiting factors in this study are: the main researcher being part of the evaluated team, as well as little national literature focused on this theme, and using the *WHOQOL-100* instrument, making it impossible to further exploit the data obtained.

A qualitative study is suggested that deepens the issues pointed out in the facets in order to clarify the influence of the work on the *WHOQOL-100* score. It emphasizes the importance of new research in the area of home care and quality of life of professionals, as well as the expansion of research to other spaces of the hospital, aiming to evaluate the quality of life of professionals and residents working in oncology. Therefore, seeking to strengthen the actions of prevention and health promotion in the workplace.

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