Quality of life and project of cancer patients in Colombia, a strategy for the creation of a public policy

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Abstract

Background: The quality of life related to health and the outcomes perceived by cancer patients, is a concept that allows knowing the patient's perception of their health situation and the conditions associated with these. This study is part of the PROCAN strategy, originally devised as response to deficiencies in state policies aimed to assess the health condition of cancer patients and the difficulties which arise while posing multidimensional interventions designed to better a patient's quality of life.

Methods: A cross-sectional study was developed in a representative sample of cancer patients in Colombia, in which the standardized generalized instrument EQ5D3L and a specific instrument called EORTC QLQ-C30 were applied. The characterization data of the population were analyzed by descriptive statistics.

Results: The defined scales were applied to 360 patients. The global health state of the EORTC QLQ-C30 was of 66.05, which compared with the control scale EQ5D3L was of 0.70 and with the analog visual scale of 69.79. EORTC QLQ-C30 were applied. The emotional and social functions were the most affected. And from a symptoms' perspective, financial difficulties created the greatest impact (52.8), followed by insomnia and fatigue, all of which were above pain.

Conclusions: Therefore, what this study intends to achieve is the promotion of the use of measurements of a cancer patient's quality of life with the purpose of, in the first place, developing process that would mitigate the damage to the most affected dimensions with the focused pathology, and the development of follow-up actions within the Colombian social security services that would aid the evaluation of proposed strategies after the original assessment of a cancer patient's quality of life.

Background

According to the report for the state of cancer in the Colombian population (2017), conducted by La Cuenta de Alto Costo (CAC), the frequency of reported cancer cases was of 229,374. Representing a considerable increase in its prevalence from 2015 with 339.8 patients, through 393.3 for 2016, up to a considerably larger 446.9 for 2017(1). Collected data indicate an increased presence for the disease, whether it may be for the increase in data collection or the conditions of the disease in and of itself.

Therefrom, actions taken at a state level allow for continuous reports, as well as consistent epidemiologic statistics within the Colombian health providers, in which actions are focused under risk assessment for control and reduction of cancer cases revolving around promotion and prevention, accompanied by primary healthcare. However, even when the government has applied strategies for the comprehensive care of patients, outlined in the decennial plan for cancer control 2012–2021(2) and law 1384 from 2010(3), there is a clear lack of strategies originating from public policies which would allow an enhancement in quality of life for Colombian oncology patients, which falls under the third objective in the decennial plan and the law hereof.

From a health-related quality of life (HRQL) standpoint, an individual patients assessment of its own wellbeing can be conducted, allowing the evaluation of changes in the aforementioned as a result of medical intervention or the healthcare system(4), demonstrating its usefulness for the assessment of the impact the disease has in a patients life as well as the shifts due to health-related interventions (5). Furthermore, the Patients Reports Outcomes (PRO) allows an understanding of a patient's own perception of how the symptoms related to its medical condition alter its quality of life, from a medical standpoint (6), meaning the HRQL, as a concept, encompass multiple aspects which altogether represent a patients perception of the effect of both disease and treatment applied to aspects such as physical, psychological and social wellbeing.

This study is part of the PROCAN strategy, originally devised as response to deficiencies in state policies aimed to assess the health condition of cancer patients and the difficulties which arise while posing multidimensional interventions designed to better a patient's quality of life. As a starting point for the said strategy there must be a measurement of the perceived outcomes for cancer patients and its variations based on the conditions in such a way that impactful strategies for the population's health can be set in motion. This manuscript shows the main results of the measurement, hence ratifying the need for this kind of data, as well as, provide the opportunity to implement them in the development of public policy in a way that would support the better health outcome for cancer patients.

Methods

Within the joint strategy (PROCAN), developed by social studies and medical researchers working alongside oncology patient's associations from around the country, a cross sectional study, approved by an ethics committee, was conducted to evaluate the perceived quality of life of cancer patients from a significant sample of the population with a wide variety of adult solid cancer patients from Colombia.

An EORTC QLQ-C30 questionnaire, a Spanish version of it, was selected, based on a literature analysis that determined the most commonly implemented questionnaire that could be applied to any type of cancer and had a version applicable for Colombia, to measure the quality of life while afflicted by cancer.

This is a multidimensional questionnaire that in 30 questions evaluates a cancer patient's quality of life in five dimensions (physical, role, cognitive, emotional, and social), three symptom scales (fatigue, pain, and nausea and vomit), and a global health condition scale (QoL), as well as individual items which purpose is to evaluate additional common symptoms (dyspnea, loss of appetite, insomnia, constipation, and diarrhea) (8). This scale works for the first two dimensions with a value between 1 to 100, where 0 reflects a negative perception of the health condition and 100 a positive perception, and for the third dimension, "Symptom scale", the values are opposite.

With the objective of applying a questionnaire that additionally of evaluating specific symptoms and dimensions, and being a PRO study, the EQ5D3L, Spanish version for Colombia, was used to measure utility and evaluate the correlation with a questionnaire of general measurements. The questionnaires were approved, in writing, for the study by the owners of their respective licenses in quantities larger than

the estimated sample size as well as previous verification of studies that ratify their validity for Colombia(12).

The sample size was estimated with a 95% confidence level and a maximum loss of 20%, achieved through the Finite Population Correction Factor in an estimate universe of cancer patients in Colombia for 2018 of 198,798(9), the sampling was done at convenience since it was taken from members of patient associations and who willingly accepted to participate through an open call in different cities (Bogotá, Cali, Santa Marta, Valledupar and Villavicencio). Eligible patients had to be adults, and have a confirmed solid cancer diagnosis, and its participation had to be ratified by a signed consent form.

The whole poll, which included the characterization data and the aforesaid questionnaires, was applied by health personnel who were previously trained in the study's objective and the application of instruments in the months of June and July from 2018. Since the information was collected by hand, all the information was transcribed into a unified database with the end of analysis, a process validated by two separate researches to prevent data loss.

For the assessment of the health conditions from EQ5D3L the recommended tariff for Colombia, obtained by Zarate *et al* (7), was implemented. And the assessment for EORTC QLQ-C30 was conducted following the EORTC data center recommendations(8).

The characterization data of the population were analyzed through descriptive statistics and analysis of statistical significance between groups based on characteristics such as sex, age, type of cancer, and reported stage were conducted. In order to evaluate the differences between assessments due to the different characteristics the program Stata Version 14 was used. The results are presented in tables and graphs.

Results

The defined scales were applied to 360 patients, 353 polls met all the quality conditions and complements which resulted in a 2% loss of collected data mainly due to not meeting they type of cancer condition. 69.41% of subjects were female with an average age of 54 compared to the males' 61. The most frequent cancers were breast, colon, cervix and prostate, consistent with what is reported for Colombia. In table 1 the rest of the characteristics for the surveyed population is outlined.

Table 1. General Characteristics [Source: Authors 2019.]

*The patient could have received several type of treatment throughout the course of the disease

**The pain was evaluated as present or absent when the surveyed was conducted

The mean values of the EORC QLQ-C30 scales are presented in the table 2 discriminated by the confidence intervals at 95%. The global health state of the EORTC QLQ-C30 was of 66.05, which

compared with the control scale EQ5D3L was of 0.70 and with the analog visual scale of 69.79 showing a very strong correlation between EQ5D3L specially with functional and symptom scales.

Table 2 Value of dimensions for EORTC QLQ-C30

The emotional and social functions were the most affected. And from a symptoms' perspective, financial difficulties created the greatest impact (52.8), followed by insomnia and fatigue, all of which were above pain, the most common symptom associated with clinical practice.

Lung cancer was that of worse value, followed by cervix; likewise, the results were consistent when observing the stages of the disease (table 3). The global health state was assessed by the patient as improved in 71.8(67.8–75.7), with the disease under control 68.8(65.9–71.7), in progressive 52.2(45.9–58.6), and in an unknow state 55.0(44.6–65.4), very similar with it in progressive. Other variables such as type of treatment, recent hospitalization and presence of pain were as well consistent with the quality of life in all dimensions.

Table 3 Valuation of EORTC QLQ C30 for type of cancer

When conducting an analysis for type of cancer and type of treatment for three dimensions included under EORC QLQ-C30 the dimension for the general health state for lung cancer either controlled or improved presents the worst value, while the cancer in a progressive stage has the lowest value for cervix cancer. When observing the functional scales in the controlled or improved stages, colon cancer has the best reported value, however, for the progressive stage cervix cancer, followed by lung cancer, have the worst reported value. Finally, when conducting the same assessment for the symptoms' scale colon cancer for its controlled or improved stages have the worse reported value, while the progressive stage in the symptomatic scale for breast cancer has the worse value.

The measurement of utility maintains similar consistency with the assessments obtained by the EORTC. In general, women are considerably more affected in all the measurements; while people with no educational level have a worse measurement and marital status does not show considerable trends (table 4).

Table 4. EQ5D3L AND EORTC QLQ-C30 by sociodemographic variables [Source: Authors 2019.]

Discussion

This paper presents the main results of Colombian cancer patients' quality of life measurement and effectively shows the affected dimensions for the portion of the population affected by cancer, and the effect social conditions or specific aspects of the disease has on said measurement. These results are imperative for the development of public policy since the dimensions most affected have, historically, not been considered for the established health plans aimed towards the population with cancer. Furthermore, these elements have not been contemplated when designing public policy whatsoever.

Amongst the most relevant results, the study found women had the worse perceived quality of life, making the findings even more impactful since breast cancer, according to the data presented by La Cuenta de Alto Costo, is the most prevalent type of cancer with 43,846 affected patients in 2016(10); by evaluating indicators that allow for an opportune care and diagnosis of the disease early detection is now more likely and continuous promotion and prevention from within the health care system, however, the results found in the study show the strategies developed have not resulted in an improvement in quality of life. Moreover, the results clearly show a socioeconomic quantifiable impact as consequence to the worsening of these patients' quality of life, and hence an opportunity to develop public policy that would widely aid the health-illness process.

Like so, the study shows that cancer, denominated in Colombia as a catastrophic disease based on the technic complexity of its treatment, the high cost of treatment, and the low cost-effectiveness of intervention (11), generates a lower perceived quality of life amongst patients with a lower education and/or advanced stages of the diseases, thus showing the need for, not only, integrated care, but, psychosocial support for the handling of the diseases. This is highly relevant as the Colombian health care system vouches for equity between regimes and access and global coverages.

Results found in both EORTC and EQ5D3L scales show the most affected dimension is the emotional function, with an emphasis in anxiety and depression, which is the most neglected in the Colombian health system's appropriate response. As a highlight, economic difficulties among the surveyed patients has the worse value in the foreseen outcomes for the symptoms dimension, a situation which is aggravated when the Colombian health care has total pathology coverage and therefore raises the need for specified studies with the purpose of determining to the highest degree the perceived financial toxicity, especially since it has different contexts, from spending out of pocket to the perceived financial ruin, because this study can only place it as the main affectation.

There have also been several studies conducted in Colombia, as is one by Bermudez and associates (12), where the quality of life was evaluated by using questionnaire QLQ-C30, conducted in cancer patients members of an institution in Bucaramanga, ratify the findings of the study since the disease was more prevalent in women with an average age of 60.89. Likewise, general results of the investigation found a measurement of 60 +/- 9.3 (CI 95% 57.01–62.99), compared to this study which found a general measurement of 66.05 (CI 95% 63.78–68.32), which are insignificant differences, and thus providing levity for the study which furthers details with a nation-wide sample.

Likewise, the results from the study concord in frequency and commitment in the perception of a worse quality of life for breast cancer patients with one conducted by Salas and associates in Antioquia(13), which was focused on evaluating the quality of life for breast cancer patients through the WHOQOL–100 scale, and providing results that showed women with the disease have a lower general scale as well as for the physical, psychological and social scales, hence ratifying the need for strategies centered around the patients rather than just providing health services.

One of the limitations of the investigation was the impossibility of using a questionnaire specially designed for the Colombian population, possibly causing an oversight of certain dimension that would otherwise be vital for the sociocultural context for Colombian patients. However, questionnaire EORTC QLQ-C30 was implemented based on the validation conducted in Colombia by Finck(14), where the scale was valued among the general population of age (18 years or older) for Colombia's main cities (Medellín, Barranquilla, Bogotá, Cali, Pereira, Cartagena and Manizales), getting a response from approximately 1000 people.

The results of the validation in the general population show a higher measure for quality of life compared to the European population with a 77.1 and starting from said measurement the effect of cancer is put into context as the quality of life decreased in more than 10 points for the Colombian population. Further comparisons with the other evaluated scales in the general population confirm the deterioration caused by this pathology since the scales for the physical function, functional role, emotional function, cognitive function, and social function for the general population are above 87, while for cancer patients it does not reach 75, being the functional role the highest with 74.3.

In the other hand, the symptom scale for the study showed that insomnia 47.22 and financial difficulties 56.94 are the worse graded by the patient, while for the general population was fatigue, but that did not reach even 15 points, and the score given by sick patients did not drop from 13 points, this being diarrhea.

It is worth noting that it is possible that within this investigation there is not a significative sample for socioeconomic status since cancer patients from a higher status to 5 do not seek support from organizations such as charitable foundations, however, considering that this part of the population does not represent even 10% of the general population, the data presented in this analysis allow focus towards public policy that would tend to the all citizens.

The use of this measurements allows for keeping up with cancer patients as well as the evaluation of this strategies, by using evaluation instruments for quality of life and PRO as the ones used in this investigation.

Conclusion

Therefore, what this study intents to achieve is the promotion of the use of measurements of a cancer patient's quality of life with the purpose of, in the first place, developing process that would mitigate the damage to the most affected dimensions with the focused pathology, and the development of follow-up actions within the Colombian social security services that would aid the evaluation of proposed strategies after the original assessment of a cancer patient's quality of life. The current care models and their respective care routes have been centered around the definition of heal-focused interventions, diagnostic methods and medication and with this study it has been proven the importance of incorporating follow-up and intervention of symptoms that have not even normally recognized as a cancer patient's indicator as could be insomnia or financial toxicity.

Likewise, considering that cancer is a chronic pathology which consumes resources and that there is a global policy of cancer integral protection, the results of this study demonstrate the need for generating public policy that would allow for the incorporation of this type of measurements into care and the construction of specific intervention in patients with the purpose of positively impacting their quality of life.

The mere existence of patient groups oriented to the protection of quality of life while afflicted by cancer becomes primordial within the model and it becomes proven the necessity for their strengthening and increased accessibility within the Colombian health care system.

The therapeutic value is as important for the evaluation of sanitary technology, this study opens an investigational branch that would include the perception of a cancer patient, which would go in line with the propositions made by a cancer oriented public policy where integral attention for cancer is prioritized and the integral protection of the population is organized, therefore, assuring its coverage and quality of life.

Declarations

Ethics approval and consent to participate

This study was approved by an ethics committee Riesgo de Fractura with the number 30983.

This manuscript does not report on or involve the use of any animal or human data or tissue or this section is not applicable to your submission.

For all participants the consent written was obtained according to study protocol.

Consent for publication

“Not applicable”

Availability of data and materials

Please contact author for data requests martin.romero@proyecta-me.com

Competing interests

The authors declare that they have no competing interests

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Authors Contributions

All the authors, collaborated, in the construction of the article, LH and DG made the literature search, LH and DG made data collection, RC, MR and MVO made data analysis, and data interpretation, the article was developed by all the authors.

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Tables

Due to technical limitations, Tables 1 - 4 are only available for download from the Supplementary Files section.

Supplementary Files

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