

Factors Related to the Quality of the Dying Process in Cancer Patients

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This correlational and descriptive research examined the Quality of the Dying Process (QDP) in cancer patients. Data were collected from one significant person for each of the 78 patients who had died, using QDP and communication quality questionnaires. The highest QDP scores were found for social experiences related to: the moment of death, family company and their concern with the person. The lowest score was for symptoms. A statistically significant association ($p < 0.001$) was found between a better QDP and: preparation for death, spending time with the family, concern and care for the patient, communication quality. Conclusions: patient care needs to be focused on the aspects fostering closeness and dialogue with the patient's close relatives, promoting communication in order to detect and handle the real problems, along with efficient pain management, in which humanized care is essential.

Descriptors: Quality of Life; Palliative Care; Terminal Care; Humanization of Assistance; Pain.

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Fatores relacionados à qualidade do processo de morrer na pessoa com câncer

Estudo descritivo, correlacional, que indagou a qualidade do processo de morrer (QPM) em pessoas com câncer. A informação foi obtida através de uma pessoa significativa para cada um dos 78 pacientes falecidos, aplicando questionários de QPM e Qualidade da Comunicação. Foram obtidas maiores pontuações da QPM nas experiências sociais relacionadas ao momento de morte, à permanência da família e à preocupação pela sua pessoa. A pontuação mais baixa se relacionou aos sintomas. Obteve-se relação estatisticamente significativa ($p < 0,001$) para melhor QPM em: preparação para morrer, estar com a família, preocupar-se pela pessoa e qualidade de comunicação. Conclui-se que os cuidados requerem orientação para que os entes queridos fiquem perto e possam se comunicar com o paciente, promover comunicação para detecção de problemas percebidos, a fim de identificar e manejar os reais problemas, somando-se ao eficiente manejo da dor, fazendo do cuidado humanizado uma prática iniludível.

Descritores: Qualidade de Vida; Assistência Paliativa; Assistência Terminal; Humanização da Assistência; Dor.

Factores relacionados a la calidad del proceso de morir en la persona con cáncer

Estudio descriptivo, correlacional que indagó la Calidad del Proceso de Morir (CPM) en personas con cáncer. La información fue obtenida con personas que eran significativas para cada uno de los 78 pacientes fallecidos, aplicando cuestionarios de CPM y Calidad de la Comunicación. Se obtuvo mayores puntajes de CPM en las experiencias sociales relacionadas con: momento de muerte, permanencia de familia y preocupación por su persona. El puntaje más bajo se relacionó con los síntomas. Se obtuvo relación estadísticamente significativa ($p < 0,001$) para una mejor CPM en: preparación para morir; estar con la familia; preocuparse por la persona; y, calidad de comunicación. Conclusiones: Los cuidados requieren orientarse hacia la necesidad del paciente de estar cerca de la familia y comunicarse con ella; así mismo se debe promover la comunicación para percibir posibles problemas e identificar y manejar los problemas reales, sumado a un eficiente manejo del dolor, haciendo del cuidado humanizado una práctica ineludible.

Descriptores: Calidad de Vida; Atención Paliativa; Cuidado Terminal; Humanización de la Atención; Dolor.

Introduction

In recent years, Chile has exhibited demographic and epidemiological changes originating in modified lifestyles, advances in health technologies and social-sanitary progress, converging in increased morbidity and mortality levels due to chronic illnesses. In this framework, cancer represents the second cause of death in the Chilean population, often translated into a difficult process at the end of life.

Patients living with cancer have to face multiple challenges, varying along with the course of the disease.

People who know their diagnosis probably sense that the disease irreversibly and inexorably advances towards death, which can arouse feelings of great vulnerability; fear of death and of physical symptoms and psychological anguish, aspects they need to adapt and go through, facing the most difficult phase in their lives, in order to die in peace and acceptance⁽¹⁾. Their coping skills will depend on their own and their environment's resources. Health teams, as competent resources, can intervene to strengthen the patient or handle the environment,

managing to improve the quality of dying⁽²⁻³⁾. Similarly, the quality of dying will depend on the patient's own social and spiritual factors, but also on factors depending on care quality⁽³⁾, related to economic costs, accessibility and quality of the communication between patients and the health team. Care processes, in turn, include the management of symptoms like pain, diet, constipation and others. In addition, preparation for death constitutes another element needed to achieve quality in the dying process.

Efforts made in Chile to improve the quality of life of patients with advanced cancer include the Pain Relief and Palliative Care Process, since 1995, and the incorporation of cancer as a GES (Explicit Guarantees in Health) disease⁽⁴⁾. However, the achievements of the Program, ongoing in Chile for more than 10 years, have been mainly assessed through quantitative measures, without clearly evaluating care quality, related factors and repercussions for the dying process from the patient's and the family's perspective.

The quality of life of patients enrolled in the Pain Relief Program has recently been assessed in Chile⁽⁵⁾, with hardly satisfactory results for its maintenance, without going deeper in the final moments of life due to the patients' fragile conditions and, therefore, not going deeper into aspects that need to be known in order to help patients prepare for the dying process.

Getting to know the quality of the dying process in patients with cancer, assessed through the experience other people informed after death, could help to identify important aspects for people during their progress to death, what factors are related to the quality of dying and how the received care was perceived, so as to guide health interventions to improve this care.

In Chile, no research has been published about the quality of dying for cancer patients, which is why the goal of this research is to get to know the quality of cancer patients' dying process and related factors to indirectly assess support programs in this area.

Material and Method

A descriptive, retrospective correlational study of people who died of cancer was carried out, informed through significant others, at the Health Service in Concepción, Chile, in 2004. The research project was reviewed and approval was obtained from the Research Ethics Committee at the Medical School of the University of Concepción, respecting ethical guidelines through the signing of the informed consent term; explanations

about the study objective, request to participate in an interview, acknowledgement of patients' rights to cease participation at any time, without affecting their health care, covering the care needed for relatives who might feel their emotional integrity is infringed upon. Moreover, participants were informed that the benefits the research would provide for health practice would be received by people and family members in the same situation as they were in.

Universe and sample: The records of the Concepción Health Service for 2004 informed 702 deaths by cancer. From this group, people younger than 18 years and those living outside the community of Concepción were excluded, so that the sample comprised 277 people. Sixty percent (155) of these could not be located because of incomplete or incorrect addresses; among identified addresses, nobody was found at home in 6.8% (19); and 7.5% of people who were located (21) refused to answer due to different reasons. In view of the above, the final sample comprised 28 % of the entire universe, corresponding to 78 people who agreed to participate, whose main characteristic was that they had accompanied the dead person during most of the disease and who were called significant others.

Interviews took place between 2 and 22 months after the patient had died (time the researchers used to contact the people and hold the interviews), at the significant other's home. The criterion for being considered significant others was according to literature⁽³⁾. This group included all people in charge of care for the dead person during the largest part of the disease. Family members of users who did not accept to participate in the study were excluded; as well as people younger than 18 years and with intellectual disabilities.

During the home interviews, questions were asked about what had happened in the last seven days of life, according to the original questionnaire and the authors' conceptual model⁽³⁾, applying two questionnaires: The Quality of the Dying Process and Death Questionnaire (QODD), and the User-Health Team Communication Quality Questionnaire⁽³⁾. The first instrument covered sociodemographic characteristics and 6 dimensions to measure the Quality of the Dying Process. It included symptoms and personal care; preparation for death; the moment of death; spending time with the family; treatment preferences and concern with the person as a whole. Each dimension asked about two aspects: the first asked how often the interviewee had experienced this situation and the second how this situation was related with the quality of the dying process.

The User-Health Team Communication Quality Questionnaire⁽³⁾ revealed how the family members of the dead person assessed the quality of communication with the health team and satisfaction with care. In both questionnaires, a higher score corresponded to better quality.

A pilot test was applied to determine the validity and reliability of both questionnaires, as well as to assess the questions' understanding and clarity among significant others for patients who died of cancer at Health Offices different from the center where the research was carried out. After the pilot test, some questions were changed for the sake of a better understanding. Reliability was assessed through Cronbach's Alpha coefficient, with 0.87 for the first instrument and 0.91 for the second. Data were analyzed in SPSS[®] 11.0, with frequency distribution, central trend and dispersion measures. In order to establish the relation between variables, inferential statistics were used with parametrical: Student's "t" and ANOVA, Pearson's "r" and non-parametrical correlation analysis: Spearman's correlation. Statistical significance was set at $p < 0.05$.

Results

With regard to the sociodemographic profile of the people who died: 70% were older than 65 years, in line with a higher percentage of people with cancer diagnoses in the national context; 51 % were women; 94% expressed some religious and/or spiritual practice; 61% perceived their economic situation as regular to bad and 64% had received care in the Pain Relief and Palliative Care Program.

When analyzing the dependent variable Quality of the Dying Process (QDP), measured through the QODD questionnaire, an almost normal distribution was observed, with a high reliability level (Cronbach's Alpha = 0.87). On a scale from 0 to 100, with higher scores indicating a better quality of dying, total QDP results ranged from 40 to 99.2 points, with an average score of 74.9 and standard deviation of 13.8 points. These results are similar to those obtained⁽³⁾ in the USA, which ranged from 26.0 to 99.6 points.

The results of the 6 component dimensions of the QODD questionnaire are shown in Figure 1.

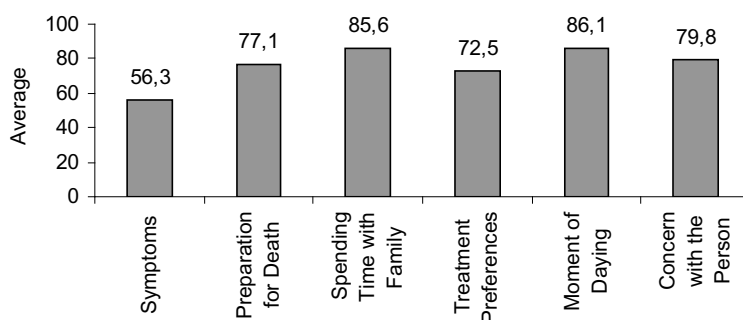


Figure 1 – Average dimension scores in Quality of the Dying Process

Figure 1 shows that, among the 6 dimensions, the highest QDP was for the experience related to staying with the family (85.6) and to the moment of death (86.1). The lowest QDP score (56.3) was obtained for the symptoms and personal care dimension.

With respect to gender and age, no significant association with QDP, nor with religious and spiritual experiences.

Participation in the Pain Relief and Palliative Care Program was not related with a better QDP. In this study, the quality of user-health team communication and satisfaction with care was related with a better QDP.

With respect to the care structure, the conformity with care frequency aspect was related with a better QDP.

Knowledge about the diagnosis and prognosis was related with a better QDP. The place of dying was significantly related with the QDP, with better scores for people who died at home than for people who died in hospital or another institution.

With regard to the physical symptoms and personal care related with the QDP, those were: Having control of complications; having pain under control; having energy or strength to do most of the things they had wanted and being able to eat, in order of priority.

The following aspects of preparation for death were related with the QDP: feeling in peace with one's death and not being afraid of dying.

The family's presence as a global dimension was related with a better QDP, especially passing time with one's partner or husband and not being alone.

The factor of concern with the person as a whole, laughing and smiling frequently helped people to achieve a better QDP.

Another aspect related with a better QDP was to find a meaning and purpose for one's life. No significant difference in QDP assessment was found according to the time period passed between death and the measurement; characteristics of the interviewees; relation with the dead person and the time spent accompanying the person before (s)he passed away.

Discussion

With regard to the results obtained in the 6 dimensions of the Quality of the Dying Process, the symptoms and personal care dimension shows the lowest score⁽⁶⁾, affecting not only quality of life but also the course of the disease. Studies⁽⁷⁾ indicate that symptoms are associated with chronic stress, characterized by the activation of the neuroendocrine hypothalamic systems, which would worsen many symptoms that are common in cancer patients, entailing repercussions not only for quality of life at the end of life, but also for prognosis.

On the other hand, the different scores in the QDP dimensions are expected, as the illness inevitably moves on, with an increasingly large number of symptoms⁽⁸⁾.

A relation was expected between the age variable and the QDP, but this was not the case, probably because the impact of facing the dying process at intermediate ages in life or at ages in which the lifecycle has not been concluded yet can be strong, affecting the QDP⁽⁹⁾.

No significant differences were found according to gender, as opposed to other authors⁽¹⁰⁾, who identify that women face more disorders in situations of suffering, perhaps corresponding to situations in which men are not allowed to express their feelings socially. Other studies⁽³⁾, on the other hand, did not find any association with this variable either. Acknowledging gender-related differences in the expression of feelings, it seemed that the process of facing death is experienced similarly.

Religious and spiritual experiences unsuspectedly were not associated with QDP. These results go against the theoretical framework used⁽²⁾ and against studies⁽¹¹⁻¹²⁾ that indicate the importance of religious beliefs to promote quality of life in the dying process, as well as to provide greater serenity and dignity before death.

Participation in a Pain Relief and Palliative Care Program was not related with a better QDP. This is in line with some authors⁽¹³⁾ who measured quality of life at the end of life in two groups and did not find any significant differences. However, as most People scored high on QDP, one might suggest that the Pain Relief and Palliative Care

Program responds to the principle of justice, as patients enrolled in the program received the necessary support, thus compensating for their care needs.

The variables quality of user – health team communication and satisfaction with care were related with better QDP, coinciding with countless authors^(2-3,14). This finding is clinically transcendent, confirming the theory⁽²⁾ that appoints that proximity with the health team through good communication could provide affrontative elements that would favor a better QDP. Various studies⁽¹⁵⁻¹⁷⁾ reflect on professional care, ranging from technical-scientific care to a care of commitment to people, which is also called the power of human care based on love in research⁽¹⁶⁾; or opposition to dysthanasia⁽¹⁷⁾ in cancer patients, which would imply favoring active listening to collect patients' problems in their different aspects: physical, social, psychological and spiritual. Thus, solutions would be proposed together with the family, deepening communication with family members and emphasizing care at the end of life. With a view to producing good communication, the health team needs special skills to face these themes, including forms of coping⁽¹⁸⁾. This would reveal the need to identify support strategies for the professionals who deliver care to these patients⁽¹⁹⁾. On the other hand, in the teams, some members might have greater or lesser communication skills with patients and families. In this respect, it should be considered that it does not matter who delivers this kind of care, nor who manages to perceive this type of need in patients, but that this information is known by the entire health team, so that the patient receives the best care.

In the care structure, conformity with care frequency was related with better QDP. This suggests that, the closer patients and their families are followed by the health team, the calmer and safer they will feel, thus receiving the information needed to be able to control problems or unexpected situations. This is also related with satisfaction with care, which suggests high-quality and sufficient care is needed to achieve a better QDP.

Knowing the diagnosis and prognosis was related with a better QDP. This aspect is considered a relevant element and one of the most important ethical dilemmas in terminal cancer patients. Saying the truth about the diagnosis implies respect for the patient's autonomy, which is not always the case. This is generally due to misunderstood paternalism or family pressure, as proven in this research, in which 32.1% never knew about their diagnosis and prognosis. This is also mentioned with higher percentages in other studies⁽⁵⁾. It is not less certain that knowing one's diagnosis might increase patients' anxiety, who could face the disease

with the support of families and significant others (98% mention such persons⁽⁵⁾, while the effect of incomplete information on psychological adjustment might persist until the moment of death. Some authors indicate⁽¹¹⁾ that the fear and anxiety that might arise from the conspiracy of silence could be mitigated by sharing these feelings with the team, thus helping to elaborate the loss⁽¹¹⁻²⁰⁾.

These findings also suppose that, when knowing one's diagnosis and prognosis, people might have passed through the mourning phases better⁽¹⁾, probably reaching acceptance. This does not mean saying that all patients should or are prepared to know their diagnosis and prognosis, suggesting⁽²¹⁾ that the cultural context should be valued in the first place, as transgressing this request might cause irreversible damage for the relation with the health team. On the other hand, patients who never knew or at least openly manifested that they were unaware of their terminal condition might have lived this process in a wall of silence, which somehow appeared through significantly lower QDP scores.

With respect to the finding about dying at home and a better QDP, agreement exists⁽²²⁾ about the conclusion that one may help people to die at home, but that adequate and equitable human and physical resources are needed for home care, as badly equipped care levels might exist. Although people manifest their desire to die at home, not everybody manages to, due to factors like: information about the illness; symptomatic and functional situation; ability to react to unforeseen events; trust in care teams: emotional adaptation and family support, which should be considered a facilitator of patients and caregivers' desire. This aspect is also associated with another study⁽²³⁾, which indicates that the use of the humanistic reference framework can help to grant cancer patients and their families a better quality of life.

With regard to the physical symptoms and personal care related with QDP, it should be highlighted that most people showed good pain control, although the research results confirmed the importance of adequately valuing symptoms, with a view to proper treatment and preventive action. In line with some authors⁽¹³⁾, who conclude that palliative care programs should mainly be directed at specific interventions in symptom management or in problems that might emerge to achieve a better quality of life at the end of life. It is supported⁽¹⁸⁾ that symptom control depends on the quality of care physicians and nurses may offer and the latter, in turn, on their ability and interest; they are often confronted with limitations, however, due to the lack of preparation in the undergraduate or graduate training with respect to the dying process⁽¹⁸⁾.

Feeling in peace with one's death and not being afraid of death were related with QDP. It is evident that measuring these aspects suggests that patients have manifested, in a subtle or open way, their feeling towards the proximity of death. It can be deduced that, as opposed to current viewpoints, knowing the final prognosis allows people to manifest their last intentions, to solve their pending issues, to say goodbye and thus experience the dying process with more quality. These aspects were related with knowledge about the diagnosis and prognosis, confirming the above.

The family's presence was related with a better QDP, particularly the fact of spending time with one's wife or husband, supporting theory⁽²⁾ and studies in this respect⁽³⁾, which justifies that people spend their last days at home together with their loved ones.

The laugh and smile factor frequently helped people to achieve a better QDP, also reaffirming studies⁽¹¹⁾ that mention that alternative interventions, including laughing, promote the best quality of life during the dying process.

Finding a meaning and purpose for one's life was related with a better QDP. This is a very important factor as it reflects an encouraging spiritual component, which is not necessarily the possibility of staying alive, but implies deeper aspects of life, in line with theory⁽²⁾ about the presence of people's affrontative resources, which can be stimulated to help and cope with situations as stressful as a death diagnosis. Through this perspective, studies indicate⁽¹⁵⁾ that one is allowed to reach the meaning of being with cancer in the dying process not as something finished, but as a being with possibilities, even in view of the factual situation of living with fate.

Health teams need to be aware of these aspects, as care can be complemented through the use of alternative therapies, boosting aspects that cannot be achieved through conventional therapies⁽¹¹⁻¹⁶⁾.

Conclusions

This research offered the start for a body of knowledge about the way people reach the final phase in their lives. Results for these people who died of cancer reflect that a better Quality of the Dying Process is mainly related with the control of symptoms, especially pain and fatigue. This dying process should be developed in the home context, involving significant others, who are trained and permanently accompanied by the health team, and who know where to turn to in order to get effective answers. Families' care capacity needs to be assessed as, if they are in no conditions to respond to the needs or symptoms that may appear, mainly in the final moments of life, the quality of dying could worsen

considerably. For health teams, this implies permanent monitoring and training of caregivers at home, as care demands considerably increase in the last days of life.

In conclusion, palliative teams need to develop climates propense to the expression of feelings, accompaniment, humanizing care delivery, permitting open dialogue, solving pending conflicts in patients and the expression of desires and tasks characteristic of the end of life. Health teams play a significant role in this phase, particularly nursing, as these teams are responsible for managing both patient and family care, requiring special preparation for managing the end of life, involving physical, psychological, spiritual and cultural aspects, the latter of which is responsible for

gestionar los cuidados tanto al paciente como a la familia, requiriendo para ello una preparación especializada en el manejo del final de la vida que contenga aspectos físicos, psicológicos, espirituales y culturales, siendo este aspecto tal vez lo que mayor impacto provoque a mediano y largo plazo para lograr la calidad en la atención paliativa y terminal que propenda a mejorar la Calidad en el Proceso de Morir.

Measuring the QDP represented a methodological challenge, with some results confirming several aspects of the construct. As patients' experiences in the dying process cannot be assessed after death, this experience needed to be assessed based on the memory of significant people.

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