

Quality of life and meaning of life: measuring the unmeasurable

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Abstract Quality of life (QoL) in medicine and in oncology is an accepted parameter for the evaluation of the benefit of treatments. Scientific methods exist to assess QoL measures in clinical trials. However, many components of the person that are properly humane and determine the patient's attitude towards the disease are not measured by current criteria. Based on clinical experience, the author considers that a shift in knowledge and in doctors' attitudes is required to also include non-measurable parameters in the doctor-patient relationship.

Keywords Quality of life · Meaning in life · Dignity therapy

Introduction

In the last three decades, several investigators have defined the value of including health-related quality of life (QoL) measurement in clinical research in oncology [1–3]. According to the US Food and Drug Administration (FDA), QoL should have the same dignity as overall survival in the evaluation of the benefits of a given therapy [4]. There are now established scientific methods for the evaluation of measures used to assess QoL in clinical trials. There are a number of existing ways to measure QoL in cancer patients, and further development of instruments is underway [5]. However, several hurdles remain before QoL can be considered an essential tool of patient-centred care in oncology and in other disciplines. This journal has already addressed these issues in several articles published in 2008, which I refer to for further details. In this article, I try to pinpoint the relative value and the dearth of QoL from the point of view of a clinical oncologist, and the possible ways for fulfilling the individual and unrepeatable needs of the patient.

Quality of life: what do questionnaires not measure?

Currently available instruments for QoL do not measure the components of the person that are properly humane, e.g., friendship, affection, gratitude, dignity, etc. These components largely determine the attitude towards life and disease. The scientific method per se is not able to take into account these variables and clearly shows its limits. Gianni Bonadonna, an internationally renowned oncologist, suffered a stroke in 1995, and since then he shifted his attention from clinical oncology to humani-

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sation on medicine. In several essays he reported his own experience as a patient, with the terminology and the attitude of a clinician: “While specialization has improved the cure rate and the survival of many diseases, it has become an impediment to the appreciation of the personal drama related to the disease. The patient ceases to have feelings, affections and aspirations and becomes a dysfunctional machine in the eyes of the specialist. It should be discussed the limited, overstated vision that claims to see in a sick person the carrier of a determined anatomical failure. As a patient, I started an investigation on this field. It was difficult, because I was not a simple observer. I was a patient, and I wanted to be cured” [6].

More deeply, QoL stems from the *mystery* of life, and for this reason is very difficult to measure. Some persons are very sick; however, they report feeling well. Some persons are very unhappy despite having enviable health. Mario Melazzini, another physician-patient, was affected by lateral amyotrophic sclerosis in 2003; despite severe limitations in his daily life, he describes his experience of his disease as follows: “Sometimes it happens that a disease that evidently limits the body may represent a real medicine for a person who has to live with it ... The disease in itself does not remove emotions, feelings, the possibility to understand that the ‘being’ is more valuable than the ‘doing’. It may well become a way to health ... It helps also to understand that nothing in life should be taken for granted, even to drink a cup of water without choking” [7].

This apparent paradox of a good QoL in conditions of otherwise miserable health depends on the *meaning* in life (MiL), another unmeasurable concept. In this context, the meaning is the relationship among things and among things and the totality [8]. In our own experience, we know that the need for a MiL cannot be suppressed, and that the disease increases rather than abolishes that need.

Is it possible to measure the unmeasurable?

The attempt to measure the MiL, with instruments analogous to those utilised for measuring the QoL, is already ongoing. In a recent paper, Stiefel et al. [9] described one of these methodological approaches, the SMiLE (Schedule for Meaning in Life Evaluation). This approach has been adopted in several clinical situations, including oncology. Cancer patients indicated and attributed more weight to areas of MiL related to relationships, while areas related to material things were listed less often.

This confirms the clinical observation that for most patients confronted with a life-threatening disease, the

feared or anticipated separation from material things is easier to accept than the separation from relationships, which are often increasingly valued [10]. Family, leisure time, friends, and partner were the most important areas that provided MiL in this analysis. Given the objectives of the study, the sample size, and the many variables influencing MiL, statistical analyses were particularly complicated, and restricted to a descriptive analysis: this reflects the hurdles of reporting in numbers an experience that goes beyond “scientific” categories. Indeed, this study concluded that “... Further studies with larger sample sizes and different designs, complemented by qualitative research, are needed to deepen our understanding of this so characteristically human topic, which is so easy to perceive and so difficult to grasp” [9]. In our daily clinical experience, we realise that the quest for meaning is even more important than the need for health.

Possible solutions: measuring beyond measure

The vital importance of relationship both for QoL and MiL cannot be overstated. They depend on communication between a patient and his/her doctor, family, friends, relatives, neighbours. How can these relationships, and the influence they determine on patients’ life, be taken into consideration? A qualitative, rather than a quantitative, approach may be more suitable in this area. Qualitative research is an evolving form of behavioural research that tries to capture a complete picture of the subject under study. It involves different techniques that go from the proposal of open questions to the analysis of language and content of a talk or a script, to the collection of an individual’s biography in that individual’s own worlds. The use of narrative appears particularly promising towards the understanding of the influence of personal history on beliefs and attitudes and ultimately on the mechanisms that allow one to cope with disease. The patient may be invited to provide a narrative of her/his experience of the disease in her/his own words, allowing the investigator to identify the most important changes the disease has operated in the person’s life. Though time consuming, qualitative research may represent the best window to the patient’s intimate world and the most effective means of reaching out to the patient’s overwhelming wants [11]. Ellis et al. have described such an approach based on personal stories [12]. Personal stories about patients’ QoL provide an experience-based approach to understanding QoL in terms of the whole person and that person’s support network, an understanding that includes emotions, reflections, conversations, spiritual beliefs, and actions. The author

makes the case that stories have the potential to open up conversations with readers – patients, family members, and health care providers – about how QoL might be examined more thoroughly and on a more complex level than allowed for by standardised measures and typologies. This approach explores what QoL can mean in day-to-day interactions, raising the questions of how we want to live, and how we view and make decisions about our own ill bodies and those bodies to whom we give care. A narrative and evocative approach can further our understanding of QoL and increase the possibility of coping better with illness.

The doctor's personal involvement

The doctor is a main actor in this relationship. Doctors are reluctant to get personally involved with patients, for many understandable reasons. However, there is a growing movement for physicians to expand their caring with attentiveness to psychosocial, existential, and spiritual suffering [13]. It is intuitive that many patients, while suffering considerable distress, do not require specific medications, but rather simply need to talk or listen to their doctor. In a recent paper, Harvey Chochinov [14] described such an approach, called “dignity therapy”, in oncology patients near the end of life:

...the provider's presence holds tremendous therapeutic power; by taking a place at the bedside, whether asking questions about what matters, or listening to heartfelt disclosures, the provider becomes the beholder. By listening to patients, our perception of who they are extends beyond the confines of their illness, thereby shifting the patient's perception of how they are seen and heard. Validation of their concerns and ascribing meaning to their experience, according to the Dignity Model, can bolster hope, even for those whose illness has long since extended

beyond the reach of cure. The reflection that patients see of themselves in the eye of the care provider must ultimately affirm their sense of dignity. At least in part, it would appear, dignity resides in the eye of the beholder.

By accepting a relationship with the patient, the doctor knows also what is knowledgeable but not measurable. The empirically based dignity model of palliative care provides a framework for this novel intervention, informing its content and therapeutic tone. To decrease suffering, enhance QoL, and bolster a sense of meaning, purpose, and dignity, patients are offered the opportunity to address issues that matter most to them or speak of things they would most want remembered as death draws near (Table 1) [15]. An edited transcript of these sessions is returned to the patient for them to share with individuals of their choosing. This study was undertaken to establish the feasibility of dignity therapy, and determine its impact on various measures of psychosocial and existential distress. Very recently, Chochinov et al. adopted a quantitative approach to validate the Dignity Model, originally based on qualitative data [16]. In this study of 211 patients receiving palliative care, demographic variables such as gender, age, education, and religious affiliation had an influence on what items patients ascribed to their sense of dignity. “Feeling life no longer had meaning or purpose” was the only variable to enter a logistic regression model predicting overall sense of dignity, thus confirming the qualitative data of the approach.

Spiritual care as a dimension of palliative care

The doctor-patient relationship inevitably involves communication about spirituality, as an integral component of the human experience. Spirituality is a patient need: it affects health care decision making and health care out-

Table 1 The Dignity Therapy Question Protocol

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- Tell me a little about your life history, particularly the parts that you either remember most or think are the most important? When did you feel most alive?
 - Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?
 - What are the most important roles you have played in life (family roles, vocational roles, community-service roles, etc)? Why were they so important to you, and what do you think you accomplished in those roles?
 - What are your most important accomplishments, and what do you feel most proud of?
 - Are there particular things that you feel still need to be said to your loved ones or things that you would want to take the time to say once again?
 - What are your hopes and dreams for your loved ones?
 - What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your (son, daughter, husband, wife, parents, other[s])?
 - Are there words or perhaps even instructions that you would like to offer your family to help prepare them for the future?
 - In creating this permanent record, are there other things that you would like included?
-

Adapted from [15]

comes, including QoL. Given the “unmeasurable” nature of spirituality, controversies exist about a commonly accepted definition of spirituality, the appropriate application of spiritual care in palliative care settings, clarification about who should deliver spiritual care, the role of health care providers in spiritual care, and ways to increase scientific rigor surrounding spirituality and spiritual care research and practice. The recommendations of a 2009 Consensus Conference [17] on including spirituality in palliative care are reported in Table 2. In clinical practice, a simple clinical instrument the physician can use to recognise the specific spiritual needs of the patient is the FICA (Faith, Importance, Community and Address in care) described by C. Puchalsky (Table 3) [18]. According to this approach, spirituality should be considered a patient vital sign. Just as pain is screened routinely, so should spiritual issues be a part of routine care. Institutional policies for spiritual history and screening should be integrated into intake policies and ongoing assessment of care. This approach is typically interdisciplinary and involves the concerted action of different subjects. The team that should be in charge of the patient include the physician, nurses, social worker, psychologist, and a member of the clergy. The latter

members in the USA receive Clinical Pastoral Training (CPT), which enables him/her to minister to the spiritual needs of patients of any religion or no religion at all. It is conceivable that such recommendations, before evolving into formal guidelines, should impact on the sensitivity of each component of the caring team.

The challenge

Putting together all these factors implies communication, relationship, personal involvement, mutual trust, and coalition. The endpoint is patient-oriented care that takes into consideration not only outcome results but also patient’s personal wishes and desires, for a better QoL and quality of care.

Conclusions

The relevance of QoL as an outcome in clinical medicine is not disputable. It is the first serious attempt to put the patient at the centre of the stage. Thanks to the QoL assessment, patients have a chance to speak and to express their

Table 2 Recommendations of the Consensus Conference for Improving the Quality of Spiritual Care as a Dimension of Palliative Care. Adapted from a Consensus Conference sponsored by the Archstone Foundation of Long Beach, California, held 17–18 February 2009, in Pasadena, California

1. Recognize spirituality as an integral component to the human experience of illness, healing, and health.
2. Perform spiritual inquiry in a patient-centred, confidential, and respectful manner.
3. Elicit the patient’s ongoing spiritual concerns-issues-needs.
4. Be sensitive to the ways in which a patient describes spiritual beliefs, practices, values, meaning, and relationships.
5. Respect patient autonomy to address or not address spirituality.
6. Practice spiritual self-care as a provider of spiritual care.
7. Collaborate with qualified interdisciplinary professionals.
8. Provide competent and compassionate spiritual care.
9. Work in partnership in the study, application, and advancement of scientific knowledge regarding spirituality and health care.
10. Perform only those services for which one is qualified, observe all laws, and uphold the dignity and honour of one’s profession.

Modified from [17]

Table 3 FICA (Faith, Importance, Community and Address in care): a spiritual history tool

F - Faith and Belief

“Do you consider yourself spiritual or religious?” or “Do you have spiritual beliefs that help you cope with stress?” If the patient responds “no”, the physician might ask: “What gives your life meaning?” Sometimes patients respond with answers such as family, career, or nature.

I - Importance

“What importance does your faith or belief have in our life? Have your beliefs influenced how you take care of yourself in this illness? What role do your beliefs play in regaining your health?”

C - Community

“Are you part of a spiritual or religious community? Is this of support to you and how? Is there a group of people you really love or who are important to you?” Communities such as churches, temples, and mosques, or a group of like-minded friends, can serve as strong support systems for some patients.

A - Address in Care

“How would you like me, your health care provider, to address these issues in your health care?” Often it is not necessary to ask this question but to think about what spiritual issues need to be addressed in the treatment plan. Examples include referral to chaplains, pastoral counsellors, or spiritual directors, journaling, and music or art therapy. Sometimes the plan may be simply to listen and support the person in their journey.

Adapted from [18]

concerns and their expectations. From the doctor's point of view, it implies a change in the pattern of knowledge, which also includes non-measurable events.

Conflict of interest None

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