

Challenges of Palliative Care

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Introduction

This communication presents a personal point of view from a psychiatric perspective about palliative care. It is intended to foster further thinking about various ways to approach and implement supportive care at the end of life. To that effect we will fall back on assumptions and premises of palliative care. The first one deals with a shifting paradigm; the second one approaches life as a chronic illness; the third one considers expectations and goals; the fourth one raises the importance of nostalgia at the end of life.

Paradigms of Palliative Care

The starting point was to provide comfort for patients who were beyond the reach of curative medicine. As the word palliation says, comfort was initially equated with covering up discomforting symptoms, chiefly pain; bodily pain first, then psychic suffering and the anguish of facing death. That extension proved difficult to cover with the same tools, and shifted the emphasis from drugs to psychological needs, and further to a systemic approach of the declining person leading to the provision of new types of services. The end point of specialized clinics for chronic diseases and cancer populations has proved so far to provide for better services and has even extended both quality and duration of life, even for cancer patients [1] and debilitating fatal diseases like amyotrophic lateral sclerosis [2]. The first paradigm shift went from individual to comprehensive care, both at personal and organizational levels.

Earlier studies [3,4] of illness trajectories had put emphasis on various ways of declining at the end of life, discriminating between cancer, chronic illness and dementia/frailty. These led to another shifting paradigm, extending palliative care to debilitating diseases other than cancer. That extension proved important to modify the way palliative care was provided. Rather than being confined end-of-life care after a period of active curative care with the patient being switched to a different treatment team as an alternative when there was nothing more to do, palliative care became integrated slowly as person-oriented care, coupled with decreasing amount of disease-directed care [5], both in cancer [1,5] and chronic diseases [6-8]. That shift meant that palliative care broke the false dichotomy between curative and palliative stands [9]. It was no longer maintaining a “cover-up” approach the isolate the person from his disease, but an “open-up” attitude to foster a better adjustment to the last phase of life. As a consequence of that shift, two phases of palliative care became more obvious: one, dealing with functional decline; another, dealing with impending death. The latter retained the first meaning of palliative care; the former extended the span of palliative care as to be called “chronic palliative care” [10]. That extension has many implications within the current technological fabric of medical care, mainly clinical, ethical and organizational. To deal with those, we slip to the second assumption.

Life as a Chronic Illness

The expansive trend of palliative care has some merit to cast about a modified approach to life, at least around two points of medical attention. At critical stages of chronic illnesses [11], whereas medical progress elicited fancies about moving death away and farther, palliative care has crept right into intensive care [12] as to balance the limits of life with its maintenance by technological devices. At

earlier stages of less acute functional decline [13], advance care planning about life-sustaining treatments and patients' choices has provided incentives for progressive acceptance of approaching death as part of life. These two points have their impact on hospital-based palliative care [14] to introduce two ethical questions: the limits of life-sustaining treatments at the end of life, and the distributive justice of allocating care to the whole population given the limits of resources. However the managerial approach relies on the assumption that, given adequate information and support, most people will proceed smoothly toward the end of life. The psychiatric perspective introduced here will underline some difficulties along that path. To sketch some of these, we will compare early onset chronic illness with late onset chronic disease. Young people living from the start with chronic disease often develop distortions of personality as coping devices to meet the challenges of living. Aging people facing chronic illness will also entice their personality traits to offset the impact of disease in their life to the extent of overuse and unsteadiness. Among those we select six attitudes, highlighting the subjective experience of having a debilitating disease with functional impairment. The first is the exception. Illness gives the right to be treated differently from the rest of population, in areas otherwise not relevant to the disease. It is often a passive stand to solicit some compensation for being sick, as to allow a *passé-droit*. The second is claim. It is an active stand to make up for an injustice of having been selected by the disease. It is often accompanied by searching for faults in the investigation or treatment process. The third is overcompensation. Cardiac patients will run the marathon; pulmonary patients will climb the Kilimanjaro. There some denial here as well as the expectation of being not so different from others. The fourth is dependence. Disease becomes a passport for overindulgence and satisfaction of passivity. The fifth is punishment. People feel guilty about being sick, as illness is experienced as castigation for having abused their own body in any way earlier in life. The sixth is the expert. The patient becomes so knowledgeable as to counsel or challenge the physician in the management of his own disease. It is the least prejudicial stand, and is often seen in type 1 diabetics who take charge of their problem. One drawback comes from setting the disease between the patient and others in many transactions of daily life. This brings us to account for the interactions of all players in the situation.

Conflicting Expectations

Many hidden problems come to light among people living with a deteriorating chronic disease or with being exposed to a diagnosis of cancer. While palliative care is introduced earlier, active total care [4] remains focused on symptom relief, quality of life, end-of-life planning and self-management education. We will focus here on an additional

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dimension, that of the subjective psychological experience of those declining patients with a chronic condition. Their expected length of life is not predictable on a short term basis. These patients have reduced physical capacities and are regular users of hospital facilities. Most of their lives have been brought to a standstill; all too often they extend to their mind what happens to their body [10]. As a result of a passive stand, gaps appear between what the patient expects, what the family hopes for, and what the physician can offer. Various conflicting situations might develop. All these stem from the patient's tendency to accommodate reality to his fantasy and wishes rather than adapting to his situation. For instance, some patients do not want to know what lies ahead, there are not ready to listen to their physician; some others nurture unrealistic hopes for new treatments, some are waiting pending a move by their physician for upgrading any means of assistance. Most of these difficulties come from stalling along any stage of the process of mourning one's life, as described by Kubler-Ross and Elizabeth [15] years ago and illustrated elsewhere [10]. Further problems arise when there are conflicting values attached to the situation by the patient and by the family around. Children usually do not see the parents aging until far into the process, some children want to have them rescued from the grave by any means, some do not understand the parent's subjective distortion of his condition, and others want to exploit the parent in a vulnerable position as grievance to do justice for them. These difficulties are usually smoothed out during the late course of a terminal illness when time allows. What is then the importance of grief?

The Value of Nostalgia

People die as they have lived. It is not given to everyone to complete the process illustrated by Kubler-Ross, from early denial to anger and bargaining, to go through depression and reach acceptance. Intensive case-studies are still meaningful and useful [16,17] to get some deeper understanding of patients' anxieties and torments along that difficult path. The main benefit is to follow patients at the stage they are stuck rather than where we want them to be. Some will fight to the end, some will flight from life. Whatever their stand most people will present with a shift in time orientation as functional decline or aging sets in. They will give weight to the past, become aloof to the present. They become nostalgic as detachment from life sets in as a sign of retreat. Patients have released their hold on the actual time, but recoil on holding precious, at times slightly algic, memories of the past, memories of their lives. At the final stage, most of them retreat into solitude, silence and sleep in a symbiotic state with themselves to complete the full circle of life. As Kubler-Ross and Elizabeth [15] has noted: "Acceptance should not be mistaken for a happy stage. It is almost void of feelings" (p. 113). She has added just after: "This also the time during which the family needs usually more help, understanding, and support than the patient himself" (p. 113); the experience of separation becomes pregnant. When the nostalgic mood fills that moment with memories of the past, suddenly condensed, some relief sets in, because nostalgia covers both the pain of the loss and the intensity of earlier contact. Nostalgia merges both separation and reunion. Moreover, it enables survivors to follow the path already traveled by the dying person. The implication is that in a context of loss and decline the process of mourning, while painful, provides a deeper and richer sense to one's life, as to make

the best of a bad hand. It also helps to reach a creative transformation of hope. Earlier set to expect a longer life, hope becomes a search for meaning of one's life to find a legacy that will survive the dying.

Conclusion

The interaction of expanded models of palliative care has proved fruitful. For instance, applying early palliative care to chronic illness patients in a simultaneous care model proved to be of interest when applied to cancer care patients [1]. The obvious benefits found both in extending survival time and lessening depression might also cover less obvious but nonetheless significant gains. Among those are we note a changing pattern for the end-of-life stage, as reported by Temel et al. [1]; a pattern which supports the idea that a full experience of physical decline prepares for a better death, as meaning is preserved when hope fades away to extend life beyond its natural course.

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