
REVIEW ARTICLES

Psychiatric aspects of chronic palliative care: Waiting for death

FRANÇOIS SIROIS, M.D.

Department of Psychiatry, Laval University and Institut Universitaire de Cardiologie et Pneumologie de Québec, Québec, Canada

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ABSTRACT

This article emphasizes the shifting paradigm of palliative care from cancer patients to vital organ failure in chronic diseases. It offers a view about a type of palliative care for patients reaching the pre-terminal phase of a chronic illness. Unlike cancer patients, time is not as sharply delineated and physical pain is not a major factor, but psychological distress is often a major component of the clinical condition. Starting from the perspective of a psychiatric consultant on medical and surgical wards, I present short clinical vignettes to introduce a discussion about psychological manifestations in patients with chronic vital organ failure. The objective is to help patients find meaning to the last stage of their life. To that effect, four key sensitive areas are presented for clinicians to assess end-of-life coping: pressure on character organization, the management of hope, mourning problems, and ill health as a screen for psychological distress.

KEYWORDS: Chronic diseases, Palliative care, End-of-life coping

INTRODUCTION

Palliative care was originally meant to deal with acute terminal care. Under this paradigm, patients are suffering from extended incurable cancerous lesions and afflicted with pain, discomfort, anxiety, and, ultimately, delirium. In that context, palliative care is provided as a subacute active alleviation of most disturbing symptoms, in compassionate support for both patients and relatives. In addition, the consultant aims to coordinate the appropriate health resource to the actual condition of those patients. However, there is a class of patients emerging outside of this range, who might benefit from a different type of palliative care. These are patients with progressive chronic conditions, whose state is beyond any major medical intervention. These patients end up hospitalized for long periods, often following a trivial

precipitating event, and they are subject to extensive loss of personal autonomy. Their families are anxious, upset, or hoping for more efficient treatments. Most of these patients are ailing from terminal cardiac, renal, or pulmonary failure. Under recurrent or protracted length of hospital stay, they are waiting for death.

Illness trajectories (Murray et al., 2005b) have been mapped for various serious medical conditions, such as cancer, chronic diseases, and dementia. Although palliative care has been initially developed to deliver adequate care for cancer patients, many factors suggest a need to extend palliative care to other cohorts of seriously ill patients. Among these factors are technological advances in therapy for heart failure and severe arrhythmias, larger availability of renal hemodialysis, and widespread use of long term oxygen therapy at home. These organ system failures produce a steady and slow decline in affected patients, punctuated with an increasing frequency of hospital admissions on the one hand, and a decreasing span of therapeutic options on the other

Address correspondence and reprint requests to: François Sirois, Institut Universitaire de Cardiologie et Pneumologie de Québec, 2725, Chemin Sainte-Foy, Québec, Qc, G1V 4G5, Canada. E-mail: sirois.rondeau@sympatico.ca

hand. Advances in therapy have made it possible to stabilize these patients again and again, but such treatments only extend the length of decline with periods of stability interspersed with acute exacerbations. Historically, treatment models have emphasized management of acute exacerbations (Howlett, 2011), leaving a gap for the larger comprehensive care of patients in their global trajectories. This gap has been plagued with prognostic paralysis (Murray et al., 2005a) and a passive approach to general global care. Recently, a larger concern to cover that gap has been voiced for various chronic conditions (Gore et al., 2000; Seamark et al., 2007; Tamura & Cohen, 2010; Howlett, 2011). This preoccupation might signal a shift in the way palliative care is seen fit to meet the needs of declining patients with chronic conditions. The old concept was that palliative care took over when curative care had reached its limits. The new concept (Murray et al., 2005b) integrates together in opposite proportions receding curative care and increasing palliative care. That means either earlier reference to palliative care as a joint venture in the follow-up of patients, or a more comprehensive approach provided by the medical curative team. That wider type of care implies an interdisciplinary organization (Nelson et al., 2010) aiming at a personal, steady, and continuous follow-up. Whereas palliative care will likely be introduced earlier in the trajectories of declining patients with chronic key organ failure, active total care (Murray et al., 2005b) remains mainly focused on symptom relief (Seamark et al., 2007), quality of life (Isaac & Curtis, 2009), end-of-life planning (Howlett et al., 2010) and self-management education (Rocker et al., 2007). These aspects of comprehensive care are all important features. The present article will address an additional dimension, that of the psychological experience of those declining patients with a chronic condition, in line with qualitative research about how people live with that condition (Elofsson & Öhlen, 2004; Morton et al., 2010; Pinnock et al., 2011).

Pre-terminal chronic palliative care (PTCPC), defined by Murray et al. (2005b), deals with patients whose medical conditions are chronic, irreversible, and deteriorated beyond any active medical intervention other than support with conventional means. Unlike cancer patients, 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. As a consequence, most of their lives have been brought to a standstill. They are in a state of physical survival. All too often they extend to their mind what happens to their body. Many of these patients are prone to withdraw into enduring (Morse, 2001), to evade mental pain, and,

as a consequence, to lack any meaningful sense of that last part of their lives, or to have unrealistic expectations about medical resources. Pre-terminal chronic palliative care attempts to restore meaning to that ultimate phase of the life of these patients. Whereas palliation means etymologically “to cover with a cloak,” to cover up, that care aims at opening up the life of the mind when life goes away from the body, in times of uncertainty, unpredictability, and undefined length of survival. Chronic palliative care aims at preventing disabled patients from just waiting for death, and helping them to experience their situation in a meaningful, if not a positive, way. To reach its palliative goal and alleviate end-of-life manifestations of distress, PTCPC targets some psychic aspects that are often concealed by the physical ailment the patient is presenting with.

The basic assumption of that approach is the following: in the context of a serious chronic condition affecting patients for which “there is not much to do,” the manner in which these patients experience their conditions provides leverage to sustain the burden of declining health and to put it in perspective of the patient’s whole life. The scope of this article deals with psychological issues of chronic care of the declining patient when levels of care have been set to exclude emergency measures to extend life, such as intubation and resuscitation, and when duration of that last phase of life cannot be assessed more precisely than “pre-terminal” (Seamark et al., 2007; Howlett, 2011). Hence, the need to explore the question: “What is left to do *with* the patient when there is nothing more to do *for* the patient?” To that effect we will present short clinical observations about various situations, and discuss some lines of intervention.

METHODS: CLINICAL OBSERVATIONS: PROBLEMS AND CHALLENGES

The protracted course of chronic vital organ failure makes putting an end to active medical interventions a delicate matter, as repetitive episodes look often similar and reversible with modern medicine there to help and propose remedies, and as patients continue to hope for either improvement or lack of deterioration. Repetitive and longer hospital stays are a solid sign that the patient is at the pre-terminal stage, but often the patient is treated from the point of view of loss of autonomy resulting from the worsening of the clinical condition and concurrent aging. Frequently, the patient arrives at the hospital ostensibly for an ailment, whereas in actuality, the patient is reacting to the psychological toll of the medical condition, or is fighting the loss of coping abilities, which have strained by progressive sickness. The following vignettes sketch various situations.

The Sentinel

An 82-year-old man was hospitalized for shortness of breath. He was known to have cardiac failure and pre-terminal renal failure. Medical treatment was symptom driven. The patient complained of insomnia. A psychiatric consultation was requested, as the patient wandered about on the ward at night. Examination ruled out cognitive deficit. A history of insomnia showed that the patient had begun experiencing disturbed sleep a month ago, at which time he had seen the nephrologist, who had discussed hemodialysis at length with him. The specialist had explained that it would not help him to live longer and would only make his life more inconvenient. The patient was a retired salesman, living with his wife in a serviced residence for the aged, and was well cared for by a daughter who drove him to various appointments. The patient alluded to the end of his life, as if realizing that the issue could not be evaded anymore. He claimed to be fit and able to perform daily chores. Insomnia was protracted, as usual hypnotics failed to assure sound sleep; he felt slightly relieved only with trazodone, 50 mg hs. He appeared to be nice, witty, and anxious about how death would come about. He talked about his father having had an amputation with much agony in his last days, and that he hoped for sudden death in his own case. He spent his nights talking with attendants, and dozed off in the mornings. Ambivalent about the course of his stay, he would clamor one day to return home, the next for increased hospital care. He did not seem in a hurry to go home. He appeared to be going through a long vigil waiting for death to come the "right" way. Once, he reported a dream in which he had seen his mother in Heaven who had not kept him with her. He requested regular visits from the consultant as if afraid of being left alone with his concerns.

This case shows how the patient's anxiety about facing the end of his life was first mistaken for possible cognitive decline on account of night-time wandering. The patient preferred to spend that time talking to the staff rather than staying by himself, as a way to distract his attention from disturbing thoughts, which were later brought in the consultation process. He also tried to derive comfort from being close to hospital staff. When the consultant talked to him about these thoughts, the patient felt relieved and expanded on how he had tried to keep away from feared suffering. His hospital stay was essentially being used by him to maneuver a smooth way out of life, if possible.

The Raging Bull

An 84-year-old man was hospitalized for troubled vision with unsteadiness of gait. A right sylvian

cerebrovascular accident was diagnosed, and left hemispheric weakness recorded. The patient experienced irritable episodes, frequently at night, when he would behave aggressively toward the staff. Delirium was ruled out, as neither consciousness nor orientation was disturbed. An anxiety reaction to his ailment was hypothesized. The patient remained impatient, unpredictable, and psychologically suffering. He asked for his wife in the middle of the night, and complained of feeling "terrible in his head," although without more elaboration. It was learned that he was a retired carpenter and still very active physically. He had a history of aggressive behavior with people, an authoritarian attitude with his wife, and impulsive reactions. On the ward, he was at times calm, although distressed, and at times threw dishes around and was disruptive. Once he said that he had feared that he had come to the hospital to die; later he requested that the consultant kill him out of mercy. Psychotropic medications were of little help at first either to dampen the main symptoms or to alleviate the underlying psychological suffering, although he was kept under risperidone 0.5 mg am and 1 mg hs, with some improvement over time. During this period, the patient had two myocardial infarctions, and only the presence of his wife brought comfort.

The patient maintained an attitude of protest throughout his hospital stay. Perhaps he thought that sheer rage might change the course of his condition. His former coping patterns were of no use and he had lost his main outlet — physical activity — to control his anxiety. His physical reactions were now useless and inappropriate. He felt that as he was not 100% fit, he had nothing left but to display a catastrophic reaction to the loss of his physical integrity.

The Neglected Complainer

A 75-year-old man with emphysema was hospitalized for infected bronchitis. Treatment extended for a longer period than usual in a context of declining pulmonary capacity. His complaints about various aspects of his treatment prompted a psychiatric consultation. The patient was talkative and overtly friendly, making gracious comments about how nice the consultant was with him. He said he felt fit enough to return home, and lamented that his children did not visit. Although his pulmonary capacity was much reduced and declining, he kept talking about his life and his former work, as if it continued up to the present. Although neglect by children took up much of his conversation, he appeared a self-centered man. Those complaints appeared to be a screen for his resentment that his life was not good enough. He had expected it would never end, and that he

would forever remain the youthful man his children represented for him. His recriminations against his children were understood to be a denial of aging, or, even more so, a denial of declining health and approaching death. The denial evolved as the making of a saga. The patient kept exposing and recapitulating his life as a tremendous adventure, probably with the aim of fascinating the listener and keeping the illusion that it was still going on.

This patient displayed a flight into fantasy; the imaginary man he put forward appeared unrelated to the patient in front of the consultant. Such a psychological device protected that man from acceptance and recognition that his life was coming to an end. It helped to maintain denial of his actual physical condition. It was not mere nostalgia, as the patient did not go back and forth between the past and the present, and did not mourn the "golden days." He only presented them as continuing, to draw the consultant near him, at times when he was feeling lonely, although without acknowledging that feeling.

The Passive Desperate

A known patient with advanced chronic obstructive pulmonary disease was re-hospitalized again for lung infection. He was retired, living alone, and with inadequate nutrition. Establishing meaningful contact with him was not easy. He would put people off with a dejected stand and answer questions with short sentences. Asking to be left alone, he managed to take minimal care of himself. He took his antibiotics but did not seem to expect anything else and refused antidepressant medications. He spent most of his time in bed and at times wondered if he would ever be able to return home. When the consultant spoke about his precarious condition, he shrugged his shoulders. He then started making suicidal threats as a way of confronting the issue of the end of his life. In this way, he raised concern among staff and kept alerted to his behavior. It was as if the patient were desperately sucking up any attention to keep him alive. He never made any actual suicidal gesture. Never able to face openly the manner in which he awaited death, he died from pulmonary edema, still wrapped in his depression.

Becoming old and ill is a loss, and some people never get over it. The nature of that loss is to be examined. This patient seemed to express the feeling that he did not exist anymore and that he did not need any help to deal with his situation. While fighting against any dependency that he appeared to fear, he could not find solace in trusting anyone to share his despair or in relying on anyone to comfort him. The loss of personal autonomy and the fading mastery over his

own body were like a betrayal from an old friend whom no one could replace.

The Anxious Expectation

A 38-year-old woman with cystic fibrosis was in the hospital for deteriorating pulmonary function. She was anxious and eager to talk about her condition. She was on a waiting list for a lung transplant. She had long-standing dyspnea, which she accepted with grace. Fear of choking had led to prescribing her very light doses of anxiolytics, which she took regularly. She knew she could not live without new lungs and was afraid they would not arrive in time. She was well acquainted with a disease that she had experienced as a symbiotic invader eating up her strength and energy. As her health declined, she came to realize that she would not receive a transplant. Her general condition steadily worsened and she died before a suitable organ was available. Acceptance of the inevitable took up more room in her thoughts and words, as evidence of her intractable ailment made her dying easier than her anxious expectation had made it seem.

Acceptance of death is easier said than done, as the previous vignettes have shown. This patient's long-standing disease helped her to face it slowly, as she could ask for and find people to share her preoccupations and concerns. From the beginning of her life she had had an illness that took its toll; therefore, it became easier for her to voice her anxiety. In her own mind, she represented the illness, and the consultant represented life that would go on without her.

RESULTS

The clinical observations showed that patients at late stages in the course of their illness might struggle at different phases of the mourning process as described by Kubler-Ross (1970). Some will not move beyond a specific phase and will stay in it, and some will find ways to integrate that phase in their life span. Sorting through these different outcomes needs discussion.

DISCUSSION

The previous vignettes raise different questions about pre-terminal clinical conditions, and various ways that people handle them and experience approaching death. Four aspects of consultation with this population will be discussed here regarding issues of palliative care appropriate for the last phase of life, as opposed to simply being confined to the subject of imminent death. These aspects are: increased vulnerability and dependence, the management of hope, reduced coping and mourning physical integrity, the

management of hope, and the frequent function of physical ailments as camouflage of psychological issues. These aspects are all related as various responses to an impending threat of the loss of life, represented by the burden of a serious deteriorating chronic illness. That burden puts pressure on usual coping mechanisms, weakens hope, which is essential for survival, and creates a difficult mourning process.

The first aspect is the toll taken by character defenses. As with impending dementia, changes in character appear as people realize that they have reached the "final stretch." Ways of coping usually stabilized by automatic character organization become challenged, unstable, and give way to emergency measures in which anxiety breaks through and undermines familiar ways of coping. Character traits become exaggerated and unpredictable. Aggressive people are more aggressive for less obvious reasons, passive people become more passive, and avoidant people become more evasive. Unlike cancer, in which the prognosis is more evident to the layperson, chronic terminal disease of a vital organ is often less conspicuous. For example, terminal renal insufficiency is often silent and painless. Hence there is more room for either hope or bargaining for more time with additional requests for continued treatment and active intervention, particularly since technological devices have been available (dialysis, defibrillators, respirators). People can now expect to negotiate additional time and hope until the last minute, believing that medicine will be able to offer something new that will extend their lives. As anxiety makes these character defenses more brittle, management of these reactions becomes difficult for two reasons. First, symptoms are expressed as behavioral problems; and second, access to the underlying force or reaction is limited, as the main concern about being curable or not is clouded by the need for emergency intervention at both symptomatic and treatment levels. When the emergency is under control, there is the possibility of addressing underlying distress. Some patients take a longer time than expected to reach this point; some die before this happens; some are troubled by the limits that medicine can offer; some are resistant to recognizing these limits as the representation of their own finite life; and some find comfort reviewing their accomplishments as they near the end. The main point is that the evolution of stable character coping into unstable behavior acts as an inflammatory reaction covering core distress and preventing meaningful work at a deeper emotional level.

The second aspect deals with the management of hope in the last phase of vital organ failure. Somehow hope rises again and again in various forms; either as an expectation of new drugs and promising research

results, or as the dream of staying medically stable, or in the form of requests for unrealistic treatments. Distortions and vicissitudes of hope are frequent in that last stage of life and provide significant information about patients, about how far or how close they are "to feeling like themselves." The first skew occurs when hope is too close to denial. It emerges as an omnipotent fantasy anchored in a position of unconscious bargaining: making unrealistic demands or putting pressure on physicians for futile alternatives. Hope is confused with keeping control over one's life. The second skew appears as "time-tumbling." Patients try to escape from where they are, to flee into the past, or to project themselves too far ahead, as if the current situation were equivalent to being in jail. Some will be unable to face it and will try to "skip out on" life before the time is up. In these cases, the temptation is to slide away into some form of unawareness, passivity, delirium-like state, or psychosis, as if to be already away when the end comes. A third vicissitude is *borrowed hope*, which is a healthier way to cope. When patients have learned to yield control to trusted caring people, they can identify with their physician (or attending nurse, relatives) and lean on their experience. Patients then adjust their expectations to what these trusted people can foretell. When hope is linked to a search for meaning it is a sounder ground from which to revise priorities and carefully plan to set things right with relatives and/or deal with other unfinished (emotional) business.

The third aspect deals with problems with mourning. Mourning life as it fades away is a painful process, as a sense of integrity is a strong component of one's self-esteem. The previous clinical vignettes reveal that people are reaching the end of their life at different stages in the mourning process described by Kubler-Ross (1970). When death occurs in the early stages (denial and anger), the pre-terminal and terminal phases are experienced in a distressing way by both patients and families, with the likelihood of behavioral symptoms preventing effective and emotional exchange between patients, their families, and the staff, and with the patient showing a dramatic fight against reality, often with a final flight into psychosis as a mode of exit (Sirois, 2009); a disturbing experience for everyone. Anticipatory grief for one's life is excruciating, because we all *feel* immortal at some times, and cling to additional time. The pain is linked to the loss of previous capacity and to the loss of control. Denial and bargaining are defenses against the former, and omnipotent wishes to set the parameters of one's death are a defense against the latter. Suicidal thoughts and requests for euthanasia will be examined keeping these defenses in mind. Acceptance of progressive

disability and limitations is easier said than done, more so with people who had physical activity to offset stress and anxiety. Deprived of their usual coping strategies, these patients either fight to the last breath or give up too early. The fine balance of adjusting one's mind to the state of the body can entail a large array of adaptive mechanisms. This disposition is often lacking in people with personality disorders, for whom coping mechanisms are restricted to a few stereotyped patterns, some of them kept in check by the physical condition.

The fourth aspect of this domain of consultation reveals that ailing health can be a screen to cover unstable psychological coping and rising anxiety when declining health is perceived as curtailing the patient's abilities, capacities, and well-cherished autonomy. The screening function tends to come to light when a "domino effect" appears during hospitalization. That domino scenario usually unfolds as follows: a rather innocuous physical symptom brings the patient to the hospital; as the patient is known for serious chronic illness, that patient is often admitted for treatment of complications, and reassessment of medication; then the persistence of psychological symptoms brings a psychiatric consultant in; finally the spouse weighs in complaining about how impossible the patient is to manage at home and argues for not taking the patient back. As the medical problem becomes a social one, an in-between level can easily disappear from view: the psychic reaction of the patient under the stressful impact of a deteriorating physical condition. The development of specialized outpatient clinics for chronic diseases with a stable central staff and long-term follow-up services has improved the early detection of these complex interactions so that recourse to consultation can occur at earlier stages. The consultant's intervention can often obviate unnecessary hospitalizations, by untangling rising crises without overtaxing existing resources, and, above all, providing comprehensive care for a vulnerable population.

All these four aspects highlight specific considerations underlying pre-terminal palliative care with patients with chronic diseases, to help them with their end-of-life experience. The consultant aims at keeping the mind alive when the body fails, tries to find meaning when hope is challenged, identifies difficulties with mourning phases and attempts to ease them, and focuses on coping difficulties when usual patterns are no use. This type of palliative care is essentially psychiatric supportive work. Psychiatric consultation with medical patients whose conditions are deteriorating aims at restoring meaning, dignity, and comfort to people.

The specific contribution of this article is that psychiatric consultation as described is geared at working with meaning (Elofsson & Öhlen, 2004),

not only with specific symptoms such as anxiety or depression, to complete overall symptom relief. The type of meaning involved is not so much an existential one (Elofsson & Öhlen, 2004), such as loneliness or resignation, but rather one that focuses on psychological coping. The consultation does not aim, as such, at providing better empowerment or self-management (Morton et al., 2010), but tries to shift the patients' attention to internal blocks in their emotional life that add to the physical burden. The consultation tries to establish the specific pattern of the patient's position, similar to what Pinnock et al. (2011) has described. That type of assessment is useful to compare the patient's position with the caring team's position, and they do not always match. For example, advanced care planning is the rule, and patients are mainly the ones to make that choice, but some don't want to know and leave it to others to decide, or just floating toward an unpredictable and unanticipated end as a way of manifesting their powerlessness. These patients will just fade away with their secret hopes.

CONCLUSIONS

Palliative care of patients with pre-terminal conditions often runs up against unsolved conflicts that have existed over a lifetime. The intervention needs, therefore, to open a wide angle on the patient's life to get a meaningful understanding, which is not to be confused with a simple glimpse at current problems. Respect for the psychic limitations of the patient may prevent access to that core. Intervention is then restricted to laying out a *pull* over the patient's life to cover the main disturbances. As pre-terminal patients are bound to be seen over multiple hospital stays, gauging the right approach to the individual patient might be done step by step. As the title of this article emphasizes, the last stretch of life is hallmarked by a passive stand, often voiced by patients in words such as: "I am waiting for God to call me." What palliative care can offer these patients is to release them to take a more active stand during that waiting, which might allow for practical and existential revision of old conflicts in view of achieving peace of mind. An active stand can still be reconciled with ultimate resignation. It opens the way for the experience of declining health as a natural pathway for closure with respect to oneself, as well as making it possible to strengthen emotional bonds with others. Dignity is a noble standard to aim at, but it is not a commodity that can be purchased or prescribed at will. People decline and die as they can afford (Sirois, 2009).

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