Palliative and Supportive Care (2012), **10**, 295–303.

doi:10.1017/S1478951511001039

Routinization and medicalization of palliative care: Losses, gains and challenges

CIRO AUGUSTO FLORIANI M.D., PH.D.,[1] AND FERMIN ROLLAND SCHRAMM, PH.D.[1,2]

[1]Bioethics Council, Brazilian National Cancer Institute, Rio de Janeiro, Brazil
[2]Social Science Department, National School of Public Health Sérgio Arouca, Oswaldo Cruz Foundation, Rio de Janeiro, Brazil

(Received May 27, 2011; Accepted June 27, 2011)

ABSTRACT

This article investigates some of the criticisms that have been directed at the hospice movement in the process of interaction with the traditional Western healthcare system, such as those relative to its routinization and medicalization. It also aims to review some of the consequences of this process of institutionalisation for the field of end-of-life care: surveillance and control over the process of dying, at the expense of decisions preferably based on the patient and that patient's ability to decide how to die, with the loss of wider objectives originally established by the movement, such as unconditional reception for the patient. Based on these criticisms, some considerations are made regarding the moral implications and risks related to this specific mode of action, the hospice way of care.

KEYWORDS: Hospice care, Palliative care, Terminal care, Health services administration

INTRODUCTION

The "good death" constitutes one – and because of its practical implications perhaps the most important – of the conceptual guidelines for the modern hospice movement. It was the desire to offer marginalized and abandoned patients a peaceful, serene death, with compassionate reception, based on the idea of the "good death," that initially triggered the movement, and the effort to fulfil this doctrine represents a genuine leitmotif for the professionals involved in its daily practice (McNamara et al., 1995; McNamara, 2001; Menezes, 2004). Furthermore, the hospice movement, drawing on its philosophical foundations, presents an argument that aims to legitimize the proposal of a care practice that involves frank communication with the patient as regards the diagnosis, prognosis, and treatment plan, in line with the patient's own wishes, all within the context of an environment of unconditional hospitality (Saunders, 1977; Floriani & Schramm, 2010).

However, Clark's question "What is a good death in a world that for many is post-religious and medicalized?" (Clark, 2003, p.174) leads us to reflect on this essential dimension of the hospice movement philosophy. In this regard, for the hospice movement, what would be a "good death?" It has been suggested that this would consist of a set of phenomenal characteristics and practical prerogatives of facing death, which would sustain the possibility of a virtuous and heroic disposition of the dying individual: the *kalós thánatos* (Kellehear, 1990; Floriani & Schramm, 2010).

There are, however, distinct wishes, which are deemed legitimate, regarding dying in contemporary society, associated with several different theoretical models of death (Walter, 1994). The "good death" model of the hospice movement is just one more in this context, which may be deemed appropriate for many, or dubious and questionable for others. For example, when understood incorrectly, an inherent risk to this model is that of transforming the hospice movement into a receptive community only for "good patients," excluding those with what is considered deviant behaviour, or "bad patients."

The conception of the "good death" – and the attitude of reception and resulting care – is realized in

---

Address correspondence and reprint requests to: Ciro Augusto Floriani, 44/1003 Dr Herotides de Oliveira, Niterói, Rio de Janeiro 24230-230, Brazil. E-mail: ciroafloriani@gmail.com

apparatus that aim to manage it more effectively. These apparatus can be seen in the interface that has been very dominant and offered great promise and that has been constructed between the modern hospice movement and the traditional Western healthcare system, modelled on disease-focused actions and continuous, persistent practices until the end of life. Indeed, after initially occupying a somewhat outcast position, the hospice movement now operates, in ever-closer partnership with this system, whether by means of an increasingly more frequent formation of palliative care teams in general hospitals, or by the growth of hospices (Wright & Katz, 2007; Doyle, 2007–2008). It is precisely in this new scenario, however, that criticisms arise regarding the practices developed by the hospice movement. It is argued, for example, that in building this interface, the modern hospice movement would be suffering a process of routinization and bureaucratization, caused by the growing instutionalization of palliative and hospice care (Abel, 1986). This ever-closer relationship could also be leading to the medicalization of the hospice movement, with the establishment of an iatrogenic process; in other words, a set of detrimental effects resulting, paradoxically, from the very application of the biomedical model to the end-of-life situations to be faced, affecting the patient and the society that depends on such care (Illich, 1975).

Therefore, the process of dying and the need to institutionalize a way of dying that is considered right and that offers some direction to the professionals involved in this practice – the way of dying a “good death”– leads us to suppose that the modern hospice movement is indoctrinating a practice that may, in fact, give rise to a subtle form of abandonment, leading to the establishment and systematization of a rather rigid care model for end-of-life patients; which was precisely the kind of criticism made in the early days of the hospice movement that legitimized its special and more receptive attitude toward such patients.

This leads one to question from an ethical standpoint the applicability of the “good death” model, because of the risk of patients being abandoned in the light of their true needs and legitimate wishes. Moreover, considering the importance that the “good death” acquires, it becomes relevant to investigate in more depth its essential elements, which give it meaning and, perhaps, social legitimacy. Therefore, the questions underlying this new investigation are: could the “good death,” advocated by the hospice movement, paradoxically lead to situations in which terminally ill patients are abandoned? Is valuing death really that important for the organization of high-quality services in palliative and hospice care? Will the institutionalization and routinization of the “good death” lead to the depletion of the foundations of the hospice movement? And, finally, to what extent would the institutionalization and consequent medicalization of palliative and hospice care actions represent an attempt to have more social control over individuals’ deaths and the way they die?

It is true that one cannot disregard the fact that the know-how of a model actively applied to end-of-life situations is also a form of institutionalization. One could, therefore, ask: what alternatives can palliative care and hospice care propose in relation to other forms of institutionalization in the field of healthcare?

This article investigates some of the criticisms that have been directed at the hospice movement in the process of interaction with the traditional Western healthcare system, such as those relative to its routinization and medicalization. It also aims to review some of the consequences of this process of institutionalization for the field of end-of-life care: surveillance and control over the process of dying, at the expense of decisions preferably based on patients and their ability to decide how to die, with the loss of wider objectives originally established by the movement, such as unconditional reception for the patient. Based on these criticisms, some considerations are made regarding the moral implications and risks related to this specific mode of action, the hospice way of care.

CRITICISMS OF THE HOSPICE MOVEMENT’S “GOOD DEATH” MODEL

There would seem to be a price to pay for the hospice movement’s striving for credibility. The movement has come under criticism particularly in relation to its institutionalization in the healthcare system. This would aim at greater exposure and integration with the prevalent medical model – the biomedical model – with what are considered dubious consequences in relation to the quality of the dying process of patients, therefore diverging from the movement’s underlying philosophy that legitimized it in the public mind. Such criticisms refer to the medicalization and routinization of the actual practice of the movement, founded on an ethos that aims at unconditional acceptance of the terminally ill patient, with clinical decisions based on limitless support for that patient. For some, this process would lead to a loss of such essential values, without which the movement is stripped of its legitimacy and the force of its innovative proposal (Hewa & Hetherington, 1990).

CHARISMA VERSUS ROUTINIZATION IN THE MODERN HOSPICE MOVEMENT

The process of ever-increasing institutionalization of palliative care and hospice care has brought about a gradual displacement of its charismatic character and its resulting routinization (James & Field, 1992).

Indeed, as Weber points out (Weber, 1979, 1982), charisma, when referring to specific individuals, sets the foundation for a relationship built between the charismatic individual and that person's followers, who recognize in the former extraordinary qualities that designate the charismatic person as a model of identification. For Weber, charisma is a historically recurrent, and (by its nature) unstable phenomenon, and the charismatic individual has a mission to perform. This person's action leads to the formation of beliefs and creates ruptures in the established social order. Those who follow the charismatic leader are entirely devoted to that leader and, therefore, dedicated to that leader's cause, revering the leader as a master. These people may also feel "called upon" to fulfil the same mission as their leader. Weber also maintains that the pure charismatic leader is completely disinterested in material and financial gain, but, when using such resources, the major source of collection is donation and the charismatic person never uses them for personal benefit (Weber, 1979, 1982). Such charismatic characteristics can be seen distinctly in Cicely Saunders, the founder of the modern hospice movement (du Boulay & Rankin, 2007).

Ass Weber observes, however, "it is the fate of charisma, whenever it comes into the permanent institutions of a community, to give way to powers of tradition or of rational socialisation (. . .) of all those powers that lessen the importance of individual action, the most irresistible is *rational discipline* [italics in the original]" (Weber, 1982: 292).

Therefore, routinization is also embodied here in the Weberian vision of the configuration of inflexible and professionalizing models, rules and routines to which certain social movements are exposed (Clark & Seymour, 2002). For Weber, this discipline demands the consistently rational and methodically trained execution of the orders received, where there is no room for personal criticism, where what is decisive "is that the obedience of a plurality of men is rationally uniform" (Weber, 1982, p. 292).

Therefore, routinization structures the form and functioning of palliative care centers and hospices, imposing challenges for the hospice movement toward a new relational model with the healthcare systems: critically, in dealing with terminally ill patients, it becomes a partner in these actions. Therefore, fresh internal and external relations are required in a scenario where "new circumstances" (James & Field, 1992, p. 1368) lead to the transformation of the originally fundamental ideals of the movement. One could say, then, that this integration between the hospice movement philosophy and the attitude of medicalization and routinization that guides healthcare system management requires a new setup, in which a "more professional" character, a "take care of" attitude, will be scrutinized by these new partners.

The complex network of continuous hospice care – which includes palliative care in the home, daycare, outpatient care, and monitoring of patients in hospital and emergency care – is actually already an integral part of the traditional healthcare systems of several countries, and for some (Abel, 1986; Bradshaw, 1996), this process tends to subsume a movement that, when originally established, or even before – at least since the days of Victorian hospices (Humpreys, 2001) – has always been on the fringe of this system. The integration between the hospice movement and healthcare systems has been partly an attempt within the movement itself to become aligned with the biomedical model, and partly the healthcare systems themselves displaying an increasing acknowledgement of the major contribution this movement provides for end-of-life care (Seale, 1991; Clark, 2007–2008; Doyle, 2007–2008).

Abel's study (1986) was the first to report the routinization processes in United States hospices. For this author, in many respects the hospices were aligned to the alternative care institutions that emerged in the 1960s and 1970s in the United States, with an attitude that demanded a more natural death in non-authoritarian and non-bureaucratized institutions, where interpersonal relations were reinforced. However, in Abel's view, their absorption into the health system made United States hospices more popular, with the side effect of reducing the critical force of the movement and its particular characteristics.

The main consequence of routinization is the bureaucratization of daily chores, in line with how Weber (1982) described the characteristics of modern bureaucracy: the ordering of regular duties by laws or administrative regulations; the hierarchization of distinct levels of authority to execute such duties; the training and consequential qualification of people to execute these tasks; the existence of a firmly ordered system of command and subordination; and internal division into sectors.

James and Field (1992) provide us with details of each of these characteristics in relation to the bureaucratization of British hospices. These control procedures are not only internal, but also forms of pressure from groups that stimulate and, through donations, help the hospice movement (Open Society Institute, 2003; National Audit Office, 2008). In this respect, the authors believe that palliative care may be losing its focus and suffering "pressures from clinical/medical audit and the 'reprofessionalization' of hospice care upon the practice of holistic care (. . .) a displacement of focus and practice (. . .) back towards more traditional medical conceptions of disease and its treatment, to the possible detriment of other 'softer' aspects of care" (James & Field, 1992, p. 1372).

A more categorical criticism of this process is presented by Bradshaw (1996). For this author, the central problem is the shift from the Christian ethos, which represented the original foundations for the hospice movement, to the ethos and corresponding institutions of secularized society. In defence of her theory, Bradshaw argues that the gradual secularization of Western European societies, which was completed in the twentieth century, had a significant effect on the work relations of nurses, a profession that is especially "in tune" with the aims of palliative care. She argues that one of the consequences is a gradual transfer of interests from a "spiritual vocation (. . .) from altruism and service to the patient" (Bradshaw, 1996, p.410) – as conceived by Florence Nightingale, considered the founder of modern nursing – to a more secular profession, with greater professional freedom. According to Bradshaw, "Cicely Saunders achieved for the dying what Nightingale had achieved a century earlier for nursing. She "secularised" the work of the religious orders (. . .) but at the same time, maintained its vocational and spiritual basis" (Bradshaw, 1996, p. 412). Here, secularization is understood in the sense of removing this care from the religious profession and placing it within a profession of laypersons, even though – as in the case of Saunders – such professionals held religious beliefs in their personal lives. Bradshaw, however, also maintains that this kind of secularization in the profession is deeply embedded in Saunders' spiritual calling, because hospices should represent the exercise of a Christian philosophy aimed at the dying, offering the terminally ill patient the hope of being received by the "Lord" (Twycross, 1986). In brief, Saunders' professional attitude introduces important tools related to research, teaching, and treatment in end-of-life care, without losing sight of the Christian and spiritual aspect inherent to this work.

For Bradshaw (1996), the current approach of the hospice movement, to the extent that it is undergoing a process of routinization, would strip its principles of the reference to this Christian exercise of end-of-life treatment, redefining four central perspectives: 1) the medical perspective; 2) the psychosocial perspective; 3) the educational and research perspective; and 4) the spiritual perspective.

In fact, one can note that the first three perspectives – and particularly the first – have been legitimized by empirically based systematized actions, with a strong incentive for research. Therefore, an approach centered firmly around the physical dimension is established, with a major focus on the most stressing symptoms.

On the other hand, there is a series of psychological intervention skills and guidelines and instructive manuals for professionals such as, for example, procedures that teach how to communicate bad news (Clarck & LaBeff, 1982; Buckman, 1984). This all aims to ensure a firm and efficient approach to the patient's mental and emotional side, considered necessary in the support given to patients. The question is whether the efficiency of an artificially learned technique can substitute for friendly and receptive spontaneity, which are so imperative during those moments nearing death. However, according to Bradshaw, this is the area of the hospice movement that has been most contaminated by what she calls *emotivism*, with all the risks of manipulation, where the concern with the correct technique prevails over a spontaneous and quiet reception, in other words, where "truth is replaced by psychological effectiveness" (Bradshaw, 1996, p. 413). It is in this "province and 'power' of the expert" (Bradshaw, 1996, p. 415) that the author identifies the significant risks of manipulation, with patients forced to "open up" their lives, in an extremely weakened state.

Therefore, a possible criticism of this model, based on the over-importance of systematized actions, is that it would result not only in the surveillance and control of the process of dying – which can be seen as a legitimate objective of biomedicine – but also in the loss of the wider objectives of a religious and spiritual nature, therefore compromising the supposedly holistic philosophy of this movement, which "masks a new, more subtle form of surveillance of dying and bereaved people in modern society" (Clark 2002a, p. 906).

In relation to the spiritual perspective, one should recall that this has always been a central aspect to hospice work. In the Victorian hospices, for example, it was channelled through the different branches of Christianity – Catholic, Methodist, Wesleyan, and Anglican – which encouraged the practice of the works performed in the everyday life of these institutions. This can be seen clearly in Goldin, when he reports a dialogue between a patient and a physician, at a hospice in 1904: " 'I'm in the best hands, doctor'. To which Barret [the doctor] replied: 'Yes, God's hands can always be entirely trusted' " (Goldin, 1981, p. 404, n. 62).

The spiritual aspect was also important in the origins of the modern hospice movement. Although, during this period in the movement's history – between 1958 and 1967 – it was still embedded in traditional Christianity, in view of the still noticeably strong influence of the religious institutions that led the work (Twycross, 1986), there was, at the same time, a concern about not "invading" patients, but rather reaching out to them, wherever they may be, in their values and physical, emotional, and existential needs (du Boulay & Rankin, 2007). And this does really seem to work, as "it is this unspoken message that brings a sense of security to those we care for (. . .) spiritual care is therefore basically non-verbal" (Twycross, 1986, p. 19). In other words, even though many professionals declared their association with Christianity, there was a concern to avoid any kind of indoctrination, to assure acceptance of anyone, regardless of their beliefs, and there was a "quieter" posture than that of today. Indeed, this was always a significant concern for Cicely Saunders and the task force that built St. Christopher's Hospice (Clark, 1999, 2001, 2002b; du Boulay & Rankin, 2007).

It was to be expected that this form of expressing religion would be redefined in the contemporary secularized societies of the West. Indeed, a more "dispersed" spirituality has surfaced in such societies, not centered on the, thereinafter prohibited, figure of an institutionalized God. Matters of an inner nature – such as the meaning of life, and the meaning of sickness – are, from now on, the emerging issues, and the patient is actively encouraged to participate in this process, which brings psychology closer to matters related to spirituality (Bradshaw, 1996).

This supposed loss of the Christian ethos in the dispersion of the hospice movement leads Bradshaw to wonder: "Can the ethic remain 'real' if it is not 'apparent'? And does it matter if it is no longer real?" (Bradshaw, 1996, p. 410).

In our opinion, the debate regarding a different or similar spirituality to that of when the hospice movement was founded is not the key issue. Nor, as Bradshaw attempts to show, do the changes in the field of spirituality seem dramatic enough to compromise the strong religious element of the hospice movement upon its creation. We do not share the idea that this increased dispersal of recognizing spirituality is necessarily problematic, or that the ethic – supposedly linked to some religious creed – has disappeared. If the traditional Christian ethic is no longer received as a transformative experience – which is not true for many – other forms of religion, or spirituality, may well be. And that does not imply any deviation from, or weakening of the foundations of, the hospice movement. Otherwise, how could one explain the existence of Buddhist, Muslim, and Jewish hospices and of atheist professionals working in hospices? (McGrath, 1998; al-Shahri & al-Khenaizan, 2005; Aminoff, 2007). Therefore, it is quite likely that other reasons, not only of a religious nature, are the driving force behind this arduous and demanding everyday work, and that does not imply – or at least should not imply – a loss of the principles that govern – or should govern – this kind of care.

The relevant question for us, and in this respect we tend to stand in the same corner as other authors (Bradshaw, 1996; Clark, 1999), is regarding excessive supply, where everything has to be done often in accordance with manuals of conduct and excessive concern with end-of-life spirituality. The meaning that each of us attributes to what may happen after our death goes a long way to determining our position on a "good" or "bad" death. As Sandman rightly points out, "the focus is on whether it is good or bad for a specific person to die under specific circumstances" (Sandman, 2005, pp. 18–19). We understand that there is an over-romanticized notion in the hospice–palliative care literature in relation to the contemporary Western person's death. Life is overvalued, whereas death is overdramatized. In our opinion, there is an excessive concern about making sure "everything goes well" on the threshold of death. On the contrary, the attitude originally proposed by the hospice movement of being available unconditionally seems much more receptive and protective than that of "we must think of new possibilities of doing everything" (Clark, 1999, p. 734). The problematic position of "saviors" – that many attribute to themselves (McNamara, 1994; Menezes, 2004) – may, when allied to a technique, lead to actions that exert a power over a person with a deteriorated body who, ultimately, yearns for reception and protection, and not necessarily salvation.

THE MEDICALIZATION OF PALLIATIVE CARE

The introduction of palliative care into the healthcare system has resulted in its medicalization. By medicalization, what is meant is a characteristic medical form of interpreting health, illness, – deviant behaviour by excellence – death, and dying, and their determining factors, which has a significant impact on the social and cultural life of a people (Clark & Seymour, 2002). Historically, this process of medicalization has prevailed foremost in mental health and public healthcare, but it extends to all fields of medicine, having been the subject of important studies, particularly since the 1970s (Illich, 1975; Zola, 1975; Conrad, 1979). These studies emerge within an enlarged understanding of medical reason that, much more than merely acting on the biological organism, also extends over the social organism, influencing it, directing it, and giving it meaning.

Therefore, the importance of medicalization is the result of the significant penetration of medical knowledge into the social body, also serving as an instrument to consolidate public health policies and social control policies, that is, biopolitical policies, as mechanisms of bio-power that ensure a systematic and permanent regulation of this social body. For Conrad (1979), this control takes place in three ways: 1) through medical technology; 2) by medical collaboration with other professions; and 3) by the medical ideology, which establishes the standards by which health is assessed and which justifies criticisms of any "deviations" from those standards. In this regard, the medicalization of daily life would not be simply a set of necessarily neutral, unintentional determining factors, but rather it would conceal forms of social and political control (Zola, 1975).

This whole medical scenario in terms of its relationship with patients and their private and social lives, bears a set of forces that interact in the form of a disciplinary power, described by Foucault (1963). Such power gives the argument and medical practice a seductive force in the eyes of society, training our thoughts and bodies and, therefore, our experiences about what health, illness, life, and death actually are (Lupton, 1997; Clark & Seymour, 2002).

In the 1950s, Parsons (1991) introduced the concept of the "sick role," describing the constitutive elements of this role to be respected by the patient and that give it institutional legitimacy.

1. An exemption from normal social role responsibilities. The physician is usually the one to legitimize this right. In other words, acceptance of his/her sick role, meaning he/she has duties to be fulfilled.
2. An exemption from responsibility to get well by one's own actions alone. In other words, the sick person cannot be expected to get better on her/his own, and has the right to assistance.
3. An acceptance that the state of being ill is not desirable, and an accompanying obligation to want to get well.
4. An obligation to seek technically competent help, namely, in the most usual case, that of a physician and to cooperate with that physician in the process of trying to get well.

It is in this last aspect that "the role of the sick person as patient becomes articulated with that of the physician in a complementary role structure" (Parsons, 1991, p. 437) becoming aligned to the role of the ordering physician, and dependent on the physician's recommendations and prescriptions.

Later, Parsons observes that "this control [of the sick person] is part of the price he pays for his partial legitimation, and it is clear that the basic structure resulting is that of the dependence of each sick person in a group of non-sick persons" (Parsons, 1991, p. 312).

Ivan Illich (1975), in a categorical critique of the way people's private and social lives are invaded by medicine, argues that medical know-how has led to society being overdependent on medical intervention – which the author qualifies as a process of iatrogenesis – in other words, a set of detrimental effects on the organizational structure and on the cultural life of this society, dictating the rules of conduct and of dependence on this social body of medical apparatus. Illich states: "social iatrogenesis is the unwanted and harmful social by-product of the social impact of medicine, more than just its direct technical action (. . .) a painful disharmony between the individual situated within his group and the physical social means which tends to be organised without him and against him. This results in a loss of autonomy in the action and in the control of the means" (Illich, 1975, p. 43).

Therefore, if on the one hand the achievements ought to be celebrated, on the other it is important to maintain a contemplative and critical attitude toward the change in palliative care within the biomedical model. In this regard, there is evidence of medicalization of palliative care, including

1. The emergence of the palliative medicine speciality in 1987, in the United Kingdom. Walter (1994) points to this recognition having taken place in the Royal College of Physicians (which gathers medical specialities applied in hospitals) and not in the Royal College of General Practitioners (who look after nonhospitalized patients).
2. The emergence of medical subspecialities, such as palliative oncology, palliative neurology, palliative nephrology, and palliative cardiology, and specialized text books regarding these fields of medical knowledge.
3. The striving for efficacy and effectiveness to legitimize palliative treatment and, therefore, a heavy emphasis on research about the end of life (Christakis, 2006).
4. The growing emphasis on the need to offer palliative care at increasingly earlier stages of treatment (World Health Organization, 2002).
5. Emphasis on the importance of the medical guidelines to systematize and guide the best clinical practice to be adopted (Emanuel et al., 2004; Kon & Ablin, 2010).

6. The way in which hospices are scrutinized, or not, by the medical audit systems, whether to liberate funds, or as part of the hospital accreditation process (Higginson, 2005; Ward & Gordon, 2006–2007).

One of the consequences of medicalization is that the interdisciplinary approach is questioned, to the extent that the view of palliative care is determined by medical know-how. In Brazil, for example, we have observed this in several congresses, meetings, seminars, and conferences, with noticeable emphasis given in lectures to the form of "medical classes," using terminology geared toward those professionals, despite an often diverse listening audience.

This medical emphasis imposes restrictions on any nonmedical professionals, as shown in a report by one such professional who was a member of the St. Christopher's Hospice team, the cradle of the modern hospice movement: "This is a medical institution, and the hierarchy is medical. Who gets the most pay? The longest sabbaticals? That's OK, if you're not pretending otherwise, but we *were*… [italics by author]. The multi-disciplinary concept has been disclosed as the great pretender. Of course, I am included in the ward rounds, which would not be the case in a hospital, but I am *invited* [italics by author] by the senior doctor to speak, and am *thanked* [italics by author] afterwards. This might be politeness, but it also reveals who has the power" (Walter, 1994, p. 165).

And how does the know-how of the hospices compare to that of conventional hospitals? In a review study, Seale (1989) observed that hospice care was not always as different from the care offered in traditional hospitals as one could have imagined. In the author's opinion, the explanations for this could lie in the fact that many hospital professionals had incorporated palliative care techniques, which would increase the effect of their practice in hospitals. For Seale, however, the main motive was the penetration of the traditional system into hospices, which had absorbed the institutionalized know-how and, as a consequence, compromised the ideal of palliative care.

But this scenario has changed. Studies conducted in the 1990s showed that there was a trend of growing satisfaction among the relatives of hospice patients, as regards the physical environment, the addressing of psychosocial matters, and the reception and care given by the doctors and nurses. Furthermore, communication had also become more open and easier in this environment. However, when assessing the phase of bereavement, the families of hospital and hospice patients alike had the same reactions of adjustment, anxiety, and psychosomatic symptoms (Seale, 1991; Seale & Kelly, 1997a,b).

However, a recent, systematic review of studies on the effectiveness of palliative care teams as regards quality of life, satisfaction with the care offered, and economic cost containment, showed that many of these studies contained methodological shortcomings, compromising any meaningful deeper analysis. The conclusion drawn was that there was not enough evidence to support the effectiveness of palliative care as regards quality of life, satisfaction of the patients and carer, and cost reduction (Zimmermann et al., 2008).

There is no doubting that this is a challenging situation. Not least because the hospice movement has proven, with its patient-centered proposal, how well it can offer good end-of-life care, where open communication is encouraged and the possibility is offered to discuss the terminal condition and the best decisions. Moreover, there are effective interventions in handling all sorts of symptoms, especially in the oncological area, in pain management and, because of all these aspects, it would seem to represent an ideal model for terminally ill patients (Powis et al., 2004; Tsai et al., 2005).

Internally, one of the tasks to be tackled by palliative care workers is overcoming the state of "become infatuated with 'team wisdom'" (Pellegrino, 1998, p. 1522). The process of routinization and medicalization of palliative care may be one of the contributing factors to this perception, with a strong trend toward disregarding patients' knowledge about their own needs, creating favorable conditions for the practice of a subtle, paternalist form of abandonment. This represents a paradox for a movement that was created precisely as a reaction against the abandonment of such patients. The challenge, therefore, lies in creating the conditions that lead to professionals recognizing that the patient is at the center, without losing sight of the personal and professional integrity of those professionals (McNamara, 1994; Pellegrino, 1998) and, at the same time, without the "good death" ideal guiding the carers' actions at the expense of the patient's real needs. Therefore, expectations that are more realistic and more compatible in this field could be built. Otherwise, the movement will run the risk of becoming an ideology of those who hold a knowledge that provides "the only right and true way to die" (Pellegrino, 1998, p. 1522) developing strict programs, with significant cracks in the underlying philosophy of the movement, thus transforming it into an instrument of power and professional manipulation over dying and death.

The growing expansion of palliative care in the traditional healthcare system is challenging, and proposes constant reviews of the best strategies for this insertion. The risk of institutionalizing palliative care within the medical model in force, subjecting it to the institutional discipline and systematization that the rules of procedure and conduct dictate, leads us to hypothesize that the hospice movement may be subsumed by the traditional hospital system, moving away from a person-centered model and away, therefore, from its original underlying principles.

In relation to the emergence of medical specialities in palliative care, these arise as a natural result of the integration with the biomedical model. As a direct consequence of this fact, palliative care is building a fragmented body of knowledge, creating "islands of knowledge," outposts of knowledge subjected to the scrutiny of a know-how that was questioned in relation to its care practice at the start of this movement.

However, as already asserted by other authors (Clark & Seymours, 2002), one cannot disregard that routinization was part of a strategy deemed necessary, and consciously desired, to confer social legitimization on the hospice movement, with all the possible consequences of this organizational process, and that routinization and charisma are not necessarily mutually exclusive.

CONCLUSIONS

Regarding the process of interaction between the hospice movement and the traditional healthcare system, it should be observed that, in all likelihood, the philosophical grounding of the hospice movement has been weakened, but that this "incarnation" in the institutionalized world, involving all the bureaucracy and routinization required for such process, may have resulted in some gains and achievements and – most importantly – may have spread a form of caring for dying people that is more compatible with their legitimate needs and wishes. That alone, if nothing else, would already represent a large step toward building more ethical relations between health professionals and terminally ill patients, grounded on actions of non-abandonment and protection. In brief, this can be seen as a logical consequence, because of the integration of the hospice movement with the traditional health system, making that system more open to the individual aspects of each patient.

There is, despite the inherent "cracks," a dialectic process between palliative and hospice care and the traditional health system, with the latter gaining new knowledge and the former gaining exposure. In a world of so much diversity and inequality, it would be naïve to believe that the spread of the hospice movement, although having broken away from its original charismatic character, and having become an institutionalized model, would remain pure in its attempt to be the most comprehensive and least discriminatory model possible upon interacting with the conventional biomedical system. Therefore, there may be a dose of naivete? in the puzzlement of many who believed that the hospice movement would be immune to the erosive processes resulting from this integration.

Nonetheless, the path found to keep the original flame alight – the construction of the "good death," as understood today – within a growing process of routinization and ever-stronger medical power, may be transforming the hospice movement into a prisoner, tied to a set of prescriptions, which instrumentalize its professions to the practice of "a kind of macabre play in which the patient is 'jollied' along until the final curtain falls" (Bradshaw, 1996, p. 418).

REFERENCES

Abel, E. (1986). The hospice movement: Institutionalizing innovation. *International Journal of Health Services, 16*, 71–85.

al-Shahri, M.Z, al-Khenaizan, A. (2005). Palliative care for Muslim patients. *Journal of Supportive Oncology, 3*, 432–436.

Aminoff, B.Z. (2007). The new Israeli law "The Dying Patient" and Relief of Suffering Units. *American Journal of Hospice & Palliative Medicine*, *24*, 54–58.

Bradshaw, A. (1996). The spiritual dimension of hospice: The secularization of an ideal. *Social Science & Medicine, 43*, 409–419.

Buckman, R. (1984). Breaking bad news: Why is it still so difficult? *British Medical Journal, 288*, 1597–1599.

Christakis, N.A. (2006). Advances in palliative care research methodology. *Palliative Medicine, 20*, 725–726.

Clarck, R.E. & LaBeff, E.E. (1982). Death telling: Managing the delivery of bad news. *Journal of Health and Social Behavior, 23*, 366–380.

Clark, D. (2002a). Between hope and acceptance: The medicalisation of dying. *British Medical Journal*, *324*, 905–907.

Clark, D. (2002b). *Cicely Saunders: Founder of the Hospice Movement – Selected Letters 1959–1999*. Oxford: Oxford University Press.

Clark, D. (2007–2008). End-of-life care around the world: Achievements to date and challenges remaining. *Omega, 56*, 101–110.

Clark, D. (2001). Religion, medicine, and community in the early origins of St. Christopher's Hospice. *Journal of Palliative Medicine, 4*, 353–360.

Clark, D. (1999). "Total pain", disciplinary power and the body in the work of Cicely Saunders, 1958–1967. *Social Science & Medicine*, *49*, 727–736.

Clark, D. & Seymour, J.E. (2002). *Reflections on Palliative Care*. Buckingham, Philadelphia: Open University Press.

Clark, J. (2003). Patient centred death. *British Medical Journal, 327*, 174–175.

Conrad, P. (1979). Types of medical social control. *Sociology of Health & Illness, 1*, 1–11.

Doyle, D. (2007–2008). Palliative medicine in Britain. *Omega, 56*, 77–88.

du Boulay, S. & Rankin, M. (2007). *Cicely Saunders: The Founder of the Modern Hospice Movement*. London: SPCK.

Emanuel, L., Alexander, C., Arnold, R., et al. (2004). Palliative Care Guidelines Group of the American Hospice Foundation: Integrating palliative care into disease management guidelines. *Journal of Palliative Medicine, 7*, 774–783.

Foucault, M. (1963). *Naissance de La clinique*. Paris: Presses Universitaires de France.

Goldin, G. (1981). A protohospice at the turn of the century: St. Luke's House, London, from 1893 to 1921. *Journal of the History of Medicine an Allied Sciences*, *4*, 383–415.

Hewa, S. & Hetherington, R.W. (1990). Specialists without spirit: Crisis in the nursing profession. *Journal of Medical Ethics*, *16*, 179.

Higginson, I.J. (2005). Clinical and organizational audit in palliative medicine. In *Oxford Textbook of Palliative Medicine*. D. Doyle, G. Hanks, N. Cherny, et al. (eds.), pp. 184–196. Oxford: Oxford University Press.

Humpreys, C. (2001). "Waiting for the last summons": The establishment of the first hospices in England 1878–1914. *Mortality*, *6*, 146–166.

Illich, I. (1975). *A expropriação da saúde – nêmesis da medicina*. Rio de Janeiro: Editora Nova Fronteira.

James, N. & Field, D. (1992). The routinization of hospice: Charisma and bureaucratization. *Social Science & Medicine, 34*, 1363–1375.

Kellehear, A. (1990). *Dying of Cancer: The Final Year of Life*. Chur: Harwood Academic Publisher.

Kon, A.A. & Ablin, A.R. (2010). Palliative treatment: Redefining interventions to treat suffering near the end of life. *Journal of Palliative Medicine*, *13*, 643–646.

Lupton, D. (1997). Foucault and the medicalisation critique. In *Foucault, Health and Medicine*. A. Petersen & R. Bunton (eds.), pp. 94–109. London and New York: Routledge.

McGrath, P.A. (1998). Spiritual response to the challenge of routinization: A dialogue of discourses in a Buddhist-initiated hospice. *Qualitative Health Research*, *8*, 801–812.

McNamara, B. (2001). *Fragile Lives: Death, Dying and Care*. Buckingham and Philadelphia: Open University Press.

McNamara, B. (1994). The institutionalization of the good death. *Social Science & Medicine*, *39*, 1501–1508.

McNamara, B., Waddell, C. & Colvin, M. (1995). Threats to the good death: The cultural context of stress and coping among hospice nurses. *Sociology of Health and Illness*, *17*, 222–244.

Menezes, R.A. (2004). *Em busca da boa morte: Antropologia dos Cuidados Paliativos*. Rio de Janeiro: Editora Fiocruz/Garamond.

National Audit Office (2008). *End of Life Care*. Norwitch: TSO (The Stationery Office).

Open Society Institute (2003). Project on death in America. *PDIA NewsletterFall*, *11*.

Parsons, T. (1991). *The Social System*. New York: Routledge.

Pellegrino, E.D. (1998). Emerging ethical issues in palliative care. *JAMA*, *279*, 1521–1522.

Powis, J., Etchells, E., Martin, D.K., et al. (2004). Can a "good death" be made better? A preliminary evaluation of a patient–centred quality improvement strategy for severely ill in–patients. *BMC Palliative Care*, *3*, 2.

Sandman, L. (2005). Should people die a natural death? *Health Care Analysis*, *13*, 275–286.

Saunders, C. (1977). Dying they live: St. Christopher's Hospice. In *New Meanings of Death*. H. Feifel (ed.), pp. 154–179. Los Angeles: McGraw–Hill Book Company.

Seale, C. (1991). A comparison of hospice and conventional care. *Social Science & Medicine*, *32*, 147–152.

Seale, C. & Kelly, M. (1997a). A comparison of hospice and hospital care for the spouses who die. *Palliative Medicine*, *11*, 101–106.

Seale, C. & Kelly, M.A. (1997b). A comparison of hospice and hospital care for the spouses who die: views of the surviving spouse. *Palliative Medicine*, *11*, 93–100.

Seale, C.F. (1989). What happens in hospices: A review of research evidence. *Social Science & Medicine*, *28*, 551–559.

Tsai, J.S., Wu, C.H., Chiu, T.Y., et al. (2005). Fear of death and good death among the young and elderly with terminal cancers in Taiwan. *Journal of Pain and Symptom Management*, *29*, 344–351.

Twycross, R. (1986). *A Time to Die*. London: Christian Medical Fellowship Publication.

Walter, T. (1994). *The Revival of Death*. London and New York: Routledge.

Ward, E.G. & Gordon, A.K. (2006–2007). Looming threats to the intimate bond in hospice care? Economic and organizational pressures in the case study of a hospice. *Omega*, *54*, 1–18.

Weber, M. (1979). *Ensaios de Sociologia*. Rio de Janeiro: Zahar Editor.

Weber, M. (1982). *Sociologia*. São Paulo: Editora Ática.

World Health Organization (2002). National cancer control programmes: Policies and managerial guidelines. Geneva: World Health Organization.

Wright, A.A. & Katz, I.T. (2007). Letting go of the rope – Aggressive treatment, hospice care, and open access. *New England Journal of Medicine, 357*, 324–327.

Zimmermann, C., Riechelmann, R., Krzyzanowska, M., et al. (2008). Effectiveness of specialized palliative care: A systematic review. *JAMA, 299*, 1698–1709.

Zola, I.K. (1975). In the name of health and illness: On some socio–political consequences of medical influence. *Social Science & Medicine*, *9*, 83–87.