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Spirituality, according to palliative caregivers. A systemic analysis.⁸

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1. Introduction

It is now commonplace to note the growing interest of healthcare professionals and healthcare administration for the question of spirituality in times of illness. A quick overview of the scientific literature and textbooks of healthcare professionals shows that for 40 years now, healthcare discourses, practices, and institutions have been open to the study and consideration of spiritual questions raised in periods of serious illness and imminent death. These questions are attracting more attention from researchers and practitioners in healthcare, at least in North America and Europe.

Because it has become an object of biomedical research, spirituality has been heavily invested by different perspectives, whether they be according to healthcare professions (spirituality according to nurses, doctors, social workers etc.), according to the different sectors of care (spirituality in oncology, psychiatry, pediatrics, palliative care etc.) or alternatively by clinical approaches centered on the identification of patients’ needs, on the validation of tools to diagnose, and on interventions pertaining to the spiritual experience of patients. While acknowledging the strengths of these descriptive approaches to spirituality in times of illness, it should be noted that to our knowledge, few studies address the role played by healthcare organizations (hospitals, long term care centers, palliative care, etc.) in shaping the different and concrete modes of expression of spirituality, or in other words, studies on spirituality from a systemic point of view.

By «concrete mode of expression of spirituality», we mean the discourses and practices related to spirituality, especially those of healthcare professionals. By the shaping role of healthcare facilities, we mean that these discourses and spiritual practice of the caregivers are influenced by normative forces operating within healthcare settings, which we name
here the « norms ». On the one hand, these forces can sometimes work together within a given establishment. On the other hand, they can be opposed amongst themselves. That being said, the intuition carried by the research team is that the current interest and integration of spirituality in the field of care and in its institutions transforms the very understanding and representation of spirituality.

Based on these various observations, we have developed a research project which aims to highlight the forces that shape the manifold spiritual discourses and practices in healthcare settings. To do this we chose to investigate palliative care (PC) organizations in order to see how the views on spirituality, the discourses that seek to render these views, as well as the practices by which the views and discourses are manifested, would be influenced by these forces present within the palliative care settings.

2. Methodology

Since there is no background literature devoted to the subject of this research, we have set up an exploratory research aiming to identify the normative forces influencing the spiritual discourses and practices. This is done from the perceptions of respondents involved in PC settings in the Quebec City area.

A total of 52 healthcare workers and volunteers in PC settings took part in individual semi-structured interviews. The data collected was aggregated according to working groups: nurses, physicians, chaplains, social workers, managers of PC units and, finally, volunteers. Although the numbers of interviews by category were relatively small, we obtained saturation for each category. A qualitative analysis of the verbatim was conducted with the help of the QDA-Miner software. The codes associated to the representations of spirituality, on the one hand, and the normative forces, on the other hand, were generated from the team members’ knowledge of the settings and of each professional culture, as well as from the interviews. Two members of the team (GJ and ACG) coded the interviews. Early in the coding process, we ran a qualitative interrator reliability test to minimize discrepancies in subsequent coding. Due to the requirements of this publication, we will limit the presentation of results to the professions of nurses, physicians and chaplains.
3. Views of spirituality
A general finding is that the view on spirituality held by our respondents is twofold. First, they share the same view on the relationship between spirituality and religion, as well as a description of the main characteristics of each one. Second, each group has a specific understanding of the function, i.e. the role that spirituality plays in PC.

3.1 Common features
A basic feature of the caregivers’ discourses on spirituality in PC settings is their common understanding and depiction of spirituality and religion. Spirituality is seen as a reality that encompasses religions and their respective traditions. It is not opposed to religions; it transcends them. Spirituality is a universal phenomenon, as well as personal; it is associated with freedom of choice and it is viewed as a process of meaning-making. It is distinct from religion as the later is considered a result of history and culture, a collective phenomenon, imposing the burden of coded rituals, dogmas and authority on individuals, and, finally, a static reality.

Table 1. Spirituality ≥ Religion

<table>
<thead>
<tr>
<th>Spirituality</th>
<th>Religion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Universal</td>
<td>Cultural/historical</td>
</tr>
<tr>
<td>Personal and related to human nature</td>
<td>Collective</td>
</tr>
<tr>
<td>Freedom</td>
<td>Constraints</td>
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<tr>
<td></td>
<td>○ Rituals</td>
</tr>
<tr>
<td></td>
<td>○ Dogmas</td>
</tr>
<tr>
<td></td>
<td>○ Authority</td>
</tr>
<tr>
<td>Dynamic (quest for meaning, questioning)</td>
<td>Static</td>
</tr>
<tr>
<td>Chosen</td>
<td>Imposed</td>
</tr>
</tbody>
</table>
This representation is in the wake of what Zinnbauer et al. already described as a modern representation of the relationship between spirituality and religiosity (Zinnbauer and Pargament, 1999).

3.2 PC-specific understanding of spirituality
This section of the paper is exclusively dedicated to our interpretation of the forces that shape the spiritual discourse for three groups of caregivers: nurses, physicians and chaplains. It aims to identify the normative forces that can account for the interprofessional discrepancies of representation (or discourse) of spirituality. Two remarks must be made before presenting the results.

3.2.1 What is a normative force?
We give a simple definition of this concept: it is a set of values and rules, (sometimes explicit, sometimes implicit) that guides people in thought and action. A normative force determines what is possible/desirable to say or do, and thus determines perforce what one cannot say or do. Some normative forces are external to an institution where PC is provided. They are present in a PC setting, however they would originate elsewhere. Examples of external normative forces are the philosophy of PC and the values it carries the deontological obligations of each profession; views of spirituality and religions existing in a given society or a given generation, etc. (Sévigny et al., 2008); Other are the intrinsic dignity of each person as a unique and autonomous individual; the value of life and the natural character of life; the need to be attentive to suffering (Lamau, 2009; Connor, 2009). Other norms are more “local” and are produced by the establishment; these include the budget decisions, administrative rules governing the provision of spiritual care, etc… However they be internal or external, norms intersect in the establishment and are part of its “daily life”. They might coalesce; they might collide as well.

3.2.2 The philosophy of palliative care
It is important to note at the start that the caregivers have, at one point of another and in a large variety of terms, referred to what the called the philosophy of PC. In the French-
speaking world, this philosophy is summarized in four tenets (Boitte and Cobbaut, p. 2009):

i) The goals of PC are different from those of preventive and curing medicine. PC aims at a good death, through the amelioration of the quality of life of patients;

ii) PC actions do not seek to prolong nor haste the end of life;

iii) Patients are considered and taken care of in a global fashion, i.e. the multidisciplinary care is provided to the whole person and not just to the illness. This is called the holistic approach of the patient. The concept of total pain, developed by Dr Cicely Saunders, is an example of this holistic approach;

iv) The patient and his or her family are integrated in the decisions pertaining to the care provided.

While the caregivers interviewed describe in other words what they consider to be the philosophy of PC, this is the theory to which they are exposed in their training.
4.1. The nurses’ discourse

The nurses’ discourse on spirituality is characterized by two major features. The first one is about the fact that a holistic approach in PC must include the spirituality of the patient. The nurses strongly adhere to a bio-psycho-social and spiritual model (Sulmasy, 2002) of care in PC settings. When asked what is the link between PC and spirituality, a common answer would be that spirituality is important to attain the goals of providing comfort and rest to the patient. Evidently, the goal of giving comfort is not restricted to physical comfort, but is enlarged to psychosocial and spiritual comfort as well.

The second feature pertains to the language used by nurses while talking about spirituality: the language of needs, especially spirituality being lived by patients as a need for interiority, a need for meaning or, at least, meaning-making. This should not be a surprise because the language of needs, used to describe the patients’ situations, has been predominant in the nursing culture and worldview, due in a large part to the seminal work of Virginia Henderson dating back to the mid 1950s.

In terms of normative forces, these features can be interpreted as manifesting respectively the philosophy of PC and a professional language that is both descriptive and normative. The nurses see these features going hand in hand, without meeting any resistance. No mention is made of forces opposed to those that support the nurses’ view of spirituality. One would have expected a discourse which would repeat one of the main elements of the philosophy of PC: a protest against a biomedical norm (which is associated with the medical goal of curing and with disease-oriented clinical actions), but this is not the case here.

4.2 The physicians’ discourse

The physicians’ discourse show a more complicated arrangement of forces than the nurses’. To begin with, features or the philosophy of PC are mentioned. Physicians associate spiritual care with interdisciplinary collaboration and with a global understanding of the patient’s suffering. Moreover, spiritual issues can be addressed by caregivers but in the full respect of the patient’s autonomy and of the patient’s initiative on this matter. While honoring the interdisciplinary characteristic of PC, this last tenet
points towards an ethical/deontological norm that plays a normative role in the physicians’ understanding of spiritual care. Another ethical caveat mentioned by our respondents is that they should not be the principal actors of spiritual caregiving. They say they will elicit information on the religious or spiritual background of a patient, in order to plan future medical interventions respectful of the patient’s belief, but that they will let any other type of spiritual assessment or intervention be performed by those professional more competent on the matter. Finally, in their view, the awareness of spiritual issues and the willingness of the PC team to make place to them sets the demarcation (or the frontier) between treatment/cure and PC.

In this case, two forces coalesce to shape the discourse on spirituality: the philosophy of PC and professional ethical/deontological norms. The resulting understanding of spirituality is mobilized to mark the difference with a «biomedical norm of treatment», that which shape what is perceived as standard medical treatment oriented towards curable or chronic illness.

4.3 The Chaplains’ discourse

The chaplains’ discourse shows a high degree of complexity. Here two sets of normative forces are in opposition. The first set comprises the philosophy of PC, a professional stance and some elements coming from Christian spiritual traditions, elements chosen in the light of the common understanding of spirituality (as detailed in section 3.1). First, the philosophy of PC is not extensively referred to by our respondents, but when it is, it is acknowledged as the framework by which it is possible to discuss about spirituality in an interdisciplinary team of care. Second, a professional stance, i.e. a set of attitudes that is specific to chaplains, is alluded to in their discourse. This stance includes a resistance to the bureaucratization of spiritual intervention. In other words, they resist to a sort of administrative definition and routinization of their tasks, which seems to deny the characteristics of freedom and spontaneity associated to spirituality as well as to the type of care that it commands. This professional stance also includes a strong position of advocacy, i.e. of representation of the interest and needs of patients, against the power of other caregivers and the establishment. This stance is somewhat similar to the ethical
stance adopted by nurses in healthcare institutions since the beginning of the bioethics era in North America. Third, some elements of Christian spiritual traditions and rituals\textsuperscript{13} (prayers, anointment of the sick, etc.) are still part of the «toolbox» of chaplains, even though, as was noted earlier, chaplains adhere to the general understanding that spirituality is a wider and more profound reality than religious traditions. Nonetheless, the spiritual dialogue with patients constitutes the major part of their clinical presence and workload.

Such spirituality is described by the respondents as opposing normative forces that are perceived as restrictions on a full deployment of their tasks. Some of these restrictions pertains to administrative norms (internal rules of management and budgetary constraints that limit the presence of chaplains in the wards), to rules of rationalization of the daily clinical presence (forms detailing the number of patients met and the time devoted to those meetings in a given period). Other restrictions pertains to a secularized culture by which is designated what chaplains perceive as an instrumentalization of spirituality, especially in biomedical literature and culture.

5. Main characteristics of the normative environment of spirituality in PC settings visited

5.1. Some general findings

Spirituality is a concern shared by all the palliative caregivers interviewed for this research\textsuperscript{14}. Following that vein, spirituality no longer belongs exclusively to a single group of caregivers, which traditionally were the chaplains. This is a situation that differs from what prevailed in the Christendom era and in the institutions that are of Christian heritage. There, medicine and religion have shared the space of accompanying the sick, each on its own time, by distinct actors, and without interfering in their respective fields of competence. However, this relationship, made of institutional proximity and distinct practice, has changed. Spirituality has become an area of interdisciplinary interest and this is due, in Quebec’s PC establishments, both to the philosophy of PC and to the secularization of healthcare institutions. Moreover, amongst the different groups of PC workers, spirituality is hardly referred to religious and spiritual traditions having marked the Western culture, except for the chaplains.
This being said, our data clearly show that there is a dual, albeit complementary, discourse on spirituality in PC settings. The first discourse puts the emphasis on spirituality closely linked to major characteristics of the philosophy of PC. Although the discourses of each professions differs on the features identified to that philosophy, there is unanimity among them on one major trait: if spiritual care is part of PC, it is because the philosophy of PC opens a space for it. The legitimacy and relevance of spiritual care in PC settings is coupled to the foundational role that its philosophy plays in end-of-life care. This philosophy enables all caregivers to be concerned about spirituality.

The second level of discourse on spirituality is outlined by plurality and diversity. The data suggests that on this level, the somewhat diverse understandings of spirituality and its function in PC units come out of arrangements mobilizing different normative forces in each case. On a more closer look, the difference can be traced back to professional norms, that is to norms that are part and parcel of professional identities.

In other words, the philosophy of PC seems to be a major influence which organises the discourse and practices of spiritual care in times of illness and imminent death. It functions as a *lingua franca* to talk about spiritual matters; it serves as a framework of integration of spiritual discussions and practices in the institution of PC and in the particular establishments. It opens a space where spirituality can be integrated in the discourses and practices and where it is susceptible to be shaped according to other norms present in a particular palliative care settings. The professional norms play a role of diversification of the function of spirituality or, said otherwise, of the goals for which spirituality is mobilized in PC settings.

6. Limits of the study

The study is limited to the area of Quebec City for the urban settings and to a rural health and social services center (general hospital, community center of health services, programs of domiciliary palliative care). So the results cannot be generalized to all Quebec PC settings, because of the internal ethno-religious plurality of the Province of Quebec.
This research is an exploratory study on small numbers of respondents for each group of caregivers. Nonetheless, saturation was achieved for the matters discussed here. This state of saturation might result from the relative cultural homogeneity of the region of investigation.

There is a selection bias: this study was carried out with voluntary research participants. So sampling design is multistage, and the sample was constituted on a non-probabilistic procedure\textsuperscript{15}. Moreover, certain groups of caregivers (nurses, physicians) were more difficult to mobilize because of their heavy workload.

Finally, due to the requirements of this publication, we were not able to present results about managers of PC units, social workers and volunteers. While concurring to the main results presented here, they would have brought a more nuanced portrait of the situation.

8. Conclusion

A systemic approach of spiritual discourses in PC settings shows diverse normative influences at work in shaping the various professional representations and function of spirituality. Two major types of norms dominate this process: the philosophy of PC, and norms pertaining to each caregiving profession involved. In a highly secularized institutional context, and as religious traditions fade away as regulatory forces of discourse and action, the discourse on spirituality does not fall in a normative no-man’s-land. On the contrary, other forces are involved: they coalesce or oppose themselves, while maintaining a kind of normative «pressure» on spirituality.

Bibliography


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8 This research is funded by the Social Sciences and Humanities Research Council of Canada (SSHRC).
9 The socio-demographic data show that saturation was not due to confounding variables. These professionals were trained in different universities and programs of PC.
10 N = 7 nurses in 3 settings
11 N = 6 physicians in 4 settings.
12 All roman catholics : 1 woman and 5 men (3 priests et 2 laymen).
13 The population of the Quebec City area still identifies itself, at least nominally, to christianity (84 % according to the 2006 census) even though the rate of weekly dominical practice is below 10%.
14 We must immediately mention a circumstantial element, unique to Quebec’s own public institutions. Health care institutions in Quebec are no longer subject to religious norms since the 1960’s. During the last 50 years, there has been a steady process of secularization of health institutions in Quebec. The religious norms that regulated healthcare institutions have progressively cleared out and left the field open to a secular institutional culture.