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The Participatory Approach (PA) : A French Department Model for Patients in Palliative Care

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Introduction

The first part of this article is a reflection on the conditions for managing palliative care patients. Apart from optimal treatment of symptoms related to the disease or treatments, with particular emphasis on optimal pain management, we would define four conditions :

i. A global approach that meets the needs of patients by offering adapted supportive care, whether psychological and social, or psycho-corporal approaches such as meditation, sophrology or self-image restoration (art therapy, socio-aesthetics).

ii. A care project and a personalized end-of-life project that requires the presence of exchange spaces where all members of the care team will be present to co-build this project with the patient.

iii. Good information, good listening and support that require, apart from training, a good availability to the other which goes through a good quality of life at work (QWL).

iv. Respect for ethical decision-making procedures that require collegiality.

In France, a circular is published in 2004 "the guide for implementing palliative care in institutions" [1] which proposes an organizational model of work collectives that is based on the establishment of a certain number of spaces for participatory exchanges essential to the proper care of patients in palliative care:

i. Patient-centered professional staffs, including all caregivers who care for the patient and their relatives. Once the patient's needs have been identified, proposals to meet those needs are discussed in a second round before a third stage, which is consensus-building on care decisions or overall management, resulting in a personalized care or end of life project.

ii. Internal team trainings to improve the skills of team members.

iii. Team support meetings. They can be imagined either in a preventive way in the form of re-reading clinical cases or ethical cases, speech groups or curative way by organizing « debriefing staffs » when a crisis situation occurs that may correspond to an end-of-life situation or a poorly managed ethical problem, a repetition of deaths, an acute conflict with a patient or family.

iv. The project approach in the form of working groups that will give autonomy to team members by giving them the opportunity to make proposals to improve patient management and quality of care.

How does the model proposed in this circular meet the needs of palliative care patients?

The multi-professional staffs allow the development of a personalized care and end-of-life project, starting from the collection of data on the needs of patients and their families by listening to each health professional. The presence of support care professionals in these staffs also helps to meet these needs. Within the model, these are the most important areas of exchange for quality of care : they allow the recognition of the role of each participant and of the nurses as they are the most important caregivers who participate in the development of the care project. They also help to make everyone aware of the values cantered on caring for others and of the importance of respect within the team.

The model allows for good listening and support. In 2021, the research team in work psychology at the University of Tours QUALIPSY published a study carried out in paediatric oncology in France. This study evaluated the impact of certain organizational determinants and the four components of the participatory approach (namely multi-professional staff, internal training, team support and project approach on quality of life) satisfaction and commitment to work of the caregivers, but also the quality of care of children assessed by a questionnaire completed by parents for children under 12 years old and by the children themselves if they were over 12 years old [2].

This study involved 510 caregivers, and 440 patients hospitalized more than 24 hours in 25 onco-medical centres. This study shows that there is a significant relationship between PA and QWL of caregivers ($p< 0.001$). Especially PA is the only organizational model of service that we know which shows an impact on quality of care assessed by patients. Multi-professional staff are thus positively correlated with the satisfaction of children and parents towards the overall attitude of caregivers ($p< 0.001$), the component « support to teams » has a positive relationship with the information given to patients ($p< 0.001$.) and the quality of communication with health personnel ($p< 0.001$). Finally, the component « internal training » is positively correlated with the quality of communication ($p<0.005$). Some other studies have shown the relationship between quality of life at work and empathy [3-4].

The multi-professional staffs also allow through the collegiality of their composition the respect of the ethical decision-making procedure: identification of the ethical problems, identification of the decision-making criteria (general, ethical, legal, deontological, scientific and contextual), identification of the people involved, discussion of possible and conceivable decisions before collegial decision-making.

Conclusion

In conclusion, the participatory approach model, an organizational work collective model, mandatory in France since 2004 for the care of patients in palliative care, perfectly meets the needs of patients at the end of life. This is a model adapted to chronic disease, geriatrics, psychiatry and disability and has been shown to improve the quality of life at work for caregivers and the quality of care assessed by patients. Although compulsory since 2004, it is unfortunately too rarely implemented in care services in France and needs greater visibility.

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