Chapter 14
Health Literacy of Oncologic Patients and Their Informal Caregivers: A Pathway for Patient Safety

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ABSTRACT

The haemato-oncological patient requires care due to the impact of the disease itself as well as the hard treatment. Health professionals and informal caregivers also play a central role in this multipart and demanding process of caring and management of the disease. Communication and health literacy to the patients and respective caregivers are crucial in promoting safe care. The development of quality improvement projects by health organizations has contributed to increase health literacy among its participants. Its implementation contributes to a closer relationship between health professionals, patients, and informal caregivers with a consequent improvement in the response to their needs.

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HEALTH CARE SAFETY

Safety has been seen as one of the fundamental principles in Health Care, being fused in two basic principles of Bioethics: beneficence and non-maleficence. Beneficence defined as “doing good” (*bene facere*), is the main objective of all health professionals. This principle involves simultaneous complementarity with the principle of non-maleficence (*primum non-nocere*), freely translated as the obligation not to intentionally inflict damage to the patient (Beauchamps & Childress, 2001).

Health care safety is understood as reducing the risk of unnecessary injury to an acceptable minimum. Based on that, factors such as current knowledge, available resources and the context in which care is provided should be considered, also as the risk of non-treatment or the option for another type of treatment (Portuguese General Directorate of Health [PGDH], 2011).

The aim of endorsing health, assuring adequate and safe care for people in situations of illness, has driven an enormous evolution of health care. In this way, we have observed the progressive development of a huge set of highly complex activities, carried out by several professionals, with high technical-scientific differentiation. In this context, human nature when combined with complex systems, with high unpredictability and variability, increases the probability of the occurrence of patient safety incidents. These being understood as the events or circumstances that could result, or have resulted, in unnecessary damage to the patient (PGDH, 2011). Therefore, there is a need to develop solutions and strategies to prevent the occurrence or recurrence of these events and contribute to a bigger resilience system (PGDH, 2011).

The improvement of this process will be more effective and efficient, if developed and implemented in a global perspective of health organizations and systems, in an integrated and articulated way between professionals, patients and caregivers.

The concept of patient safety started in hospital context (Mesquita et al., 2016; Ramos & Trindade, 2013; Sousa et al., 2018; Vincent & Amalberti, 2016). Nevertheless, its application has been built in other contexts and by other players (Vincent & Amalberti, 2015). This patient safety movement has been extended to long-term care units, primary health care and more recently to home hospitalization. The home context has gained growing importance regarding this thematic, where the relevant role of family members and informal caregivers stands out. The different health care backgrounds, performed by different players, consequently create new risks for patient safety. Health professionals, informal caregivers, families and patients must be trained regarding the current risks. Training will allow players to be able to find strategies that promote an environment in which risks, although they cannot always be eliminated, can at least be mitigated to a level where patients and caregivers feel prepared to deal with them (Stevenson et al, 2012). This paradigm change, in which health literacy and the involvement of patient/family assume themselves as a pillar for safety care, poses a challenge but is also a requirement nowadays (Lee et al, 2020).

Health Literacy and Safety of Care

According to WHO “Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health” (WHO, 1998, p.10). Accordingly, citizens need to develop skills, have access to information, resources and the opportunity to have a voice in the development of health policies, and the impact on the factors that affect their health and well-being (Sørensen et al, 2020).
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