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Titolo tesi: Loneliness in Cancer Patients Undergoing Haematopoietic Stem Cell Transplantation in Protective Isolation

ABSTRACT

Background. Haematopoietic stem cell transplantation (HSCT) has become the standard of care for many patients with haematological malignancies. However, patients undergoing autologous or allogeneic HSCT develop severe and prolonged chemotherapy-induced neutropenia after myeloablative conditioning. In order to lower infection risk, patients are often cared for in protective isolation. However, strict protective measures, such as hospital stay in single room with positive pressure, are supported by limited evidence and they are implemented inconsistently across hospitals and countries. Being isolated in a hospital room might be a lonely and distressing experience for HSCT patients. Thus, the psycho-social implications of protective isolation need to be investigated further. In addition, no tool is available to assess patients' loneliness during isolation.

Aim of the study. To explore the lived experience of protective isolation in patients with haematological malignancies undergoing autologous or allogeneic HSCT, in order to develop a self-report scale to assess loneliness during isolation.

Methods. A metasynthesis of qualitative research exploring the lived experience of protective isolation in patients undergoing HSCT was conducted following the meta- aggregative approach from the Joanna Briggs Institute. Two descriptive phenomenological studies based on Giorgi's approach were performed to explore the experience of being isolated in 9 patients who had undergone autologous HSCT at Campus Bio-Medico University Hospital and 10 patients who had undergone allogeneic HSCT at Policlinico Tor Vergata in Rome. On the basis of a tri- dimensional model of loneliness, self-report items measuring the intensity of isolation feelings were generated, both in Italian and in English. In order to verify relevance and representativeness of each item, as well as to foster item generation, a focus-group was conducted with 10 experts. Selected items were rated for their relevance and clarity by 22 experts in order to establish content validity. Cognitive interviews with five patients were conducted to verify if each item was easy to understand. The 17-item version of scale was pilot-tested in 55 patients and its validation is the aim of a multicentre study - ISOLA15.

Results. A conceptual model of loneliness, as a consequence of protective isolation, was developed in the metasynthesis. It included three dimensions: suffering, relating to oneself, and relating with others. Suffering was described with items about boredom, enhanced fears, feelings of being imprisoned, movement limitations, and isolation burden. Relating to oneself was described with items about the ability to find meaning, assuming a new perspective, finding the inner strength, and safety. Relating with others was described with items about missing someone to talk with, feeling cut off from the world, communication, and being closed to loved ones. The 17-item scale yielded a content validity of .88. Cronbach's alpha was 0.87. The pilot- test showed significant associations between items and study variables.

Conclusions. A new scale was developed for use in isolated patients undergoing HSCT. Being isolated can be a transformative experience characterised by a sense of defence. Healthcare providers should support patients to find a positive meaning to isolation. In addition, protective practises should be reconsidered in order to avoid unnecessary patient suffering.



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