



Contents lists available at ScienceDirect

## European Journal of Oncology Nursing

journal homepage: [www.elsevier.com/locate/ejon](http://www.elsevier.com/locate/ejon)

## Nursing care dependence in the experiences of advanced cancer inpatients

Michela Piredda <sup>a, b, \*</sup>, Chiara Bartiromo <sup>c</sup>, Maria Teresa Capuzzo <sup>b</sup>, Maria Matarese <sup>b</sup>,  
Maria Grazia De Marinis <sup>b</sup>

<sup>a</sup> Tor Vergata University Rome, Via Montpellier, 1, Rome, Italy

<sup>b</sup> Research Unit Nursing Science, Campus Bio-Medico di Roma University, Via Alvaro del Portillo, 21, 00128, Rome, Italy

<sup>c</sup> Campus Bio-Medico di Roma University, Via Alvaro del Portillo, 21, 00128, Rome, Italy

### ARTICLE INFO

#### Article history:

Received 24 October 2014

Received in revised form

15 June 2015

Accepted 1 July 2015

#### Keywords:

Care dependency

Advanced cancer

Hospitals

Qualitative research

Phenomenology

Semi-structured interviews

### ABSTRACT

**Purpose:** Increasing burden of cancer in Europe and socio-demographic trends imply that more cancer patients will face high levels of dependency. Care dependency is often perceived as a distressing experience by cancer patients who are concerned about becoming a burden to others. The experience of care dependence has been scarcely investigated in advanced cancer patients, especially in the hospital setting. This study aimed at describing advanced cancer patients' experiences of care dependence in hospital and of the factors perceived by them as contributing to decrease or increase this dependence.

**Methods:** The study used a descriptive phenomenological approach based on Husserl's (1913) life world perspective. Data collection and analysis followed Giorgi's (1997) five basic methodological steps. Data were gathered by semi-structured interviews with thirteen advanced cancer adult inpatients of a teaching hospital. The interviews were audio-recorded and the recordings transcribed word for word.

**Results:** Three themes emerged: 'dependency discovers new meanings of life', 'active coping with dependency' and 'the care cures the dependent person'. The essential meaning of care dependency was the possibility to become aware of being a person as both an object and subject of care.

**Conclusion:** Dependence appears as an experience with strong relational connotations, which enable patients to see differently their life, themselves, the world and others. Dependency is revealed as a natural experience, only partly in accordance with previous studies. Deeper insight into the meaning patients attach to care dependency can enable nurses to better meet the patient's needs, e.g. by improving caring relationships with patients.

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### 1. Introduction

Dependency is a key characteristic of the human being. Humans are constitutively dependent because of their relational nature and because of the frailty and vulnerability of their bodily condition (Colombetti, 2013; Kittay, 1999; Ricoeur, 1960). However, dominant contemporary culture underlines the ideal of autonomous, self-sufficient and healthy subjects (Kittay, 2011). In this vision, vulnerability and dependence are no longer considered integral parts of human life but rather a lack of humanity (MacIntyre, 1981). This can generate a tension between dependency as constitutive human condition and cultural values of independence, freedom

and autonomy. Therefore, it is not surprising that patients who are dependent on the care of others might live it as a negative experience, related to feeling powerless and worthless (Strandberg et al., 2003).

Care dependence is central to nursing (Henderson, 1966; Orem, 1995). It has been defined as a relational condition by several concept analyses (Carnes, 1984; Dijkstra et al., 1998; Bogatz et al., 2007) in accordance with George's definition (1991, p.178): "one cannot be simply dependent; one must be dependent on someone for something". For instance, Dijkstra et al. (1998, p. 144) defined nursing care dependence as "A nurse–patient relationship resulting from a person's decrease in self-care and simultaneous increase in dependence on nursing care whenever needs must be satisfied". Nursing literature reflects a growing interest in care dependence. Several qualitative studies focussing on patients' experiences of care dependence within different care settings show that

\* Corresponding author. Tor Vergata University Rome, Via Montpellier, 1, 00133, Rome, Italy.

E-mail address: [m.piredda@unicampus.it](mailto:m.piredda@unicampus.it) (M. Piredda).

dependence was mostly a difficult experience (Ellefsen, 2002; Strandberg et al., 2002, 2003; Lomborg et al., 2005). Patients found it difficult to ask for help and experienced fear of being abandoned or being punished by their carers.

### 1.1. Research problem

Care dependence is often related to patients with severe chronic conditions, such as advanced cancer (Caljouw et al., 2014). Cancer incidence and burden is growing in Europe while developments in cancer treatment and an ageing population are reducing overall mortality (Ferlay et al., 2013). This implies that the length of cancer trajectory, the number of comorbidities and disabilities in cancer patients will probably increase in the near future (Sullivan et al., 2011). Therefore, patients with cancer will be more likely to face high levels of dependence (Caljouw et al., 2014). Patients with advanced cancer who are hospitalized often have a poor performance status and therefore are dependent on care for activities of daily life (Wheatley-Price et al., 2014). Dependence on others was reported as a distressing experience by patients receiving treatment for advanced breast cancer (Luoma and Hakamies-Blomqvist, 2004) or in palliative care (Doumit et al., 2007). Moreover, “being a burden to others” was a great concern for patients with incurable lung cancer (Refsgaard and Frederiksen, 2013). The only qualitative study (Eriksson and Andershed, 2008) specifically aimed at exploring the experiences of care dependence among patients with cancer, was conducted in a palliative care setting. Research exploring the experiences of care dependence in patients with cancer is lacking (Piredda et al., 2014) and conducted only in palliative care settings. There are no qualitative studies conducted with patients with cancer in the hospital setting. However, the experience of patients’ care dependence can be dissimilar among palliative and hospital care settings, also due to the different nursing care and organization between these settings. Therefore, we do not know how hospitalized patients with advanced cancer perceive their dependence on nursing care.

### 1.2. Research purpose

A better understanding of perceptions among patients with advanced cancer and their experiences of dependence including factors that can increase or decrease this dependence could help hospital nurses to improve the care provided. For instance, empathising with patients who are dependent on nursing care may enhance care. Therefore, the purpose of this study was to describe the experiences of patients with advanced cancer pertaining to being dependent on nursing care in the hospital setting including the factors perceived by them as contributing to decrease or increase this dependence.

## 2. Methods

### 2.1. Design

According to the descriptive aim the study design was qualitative and followed a descriptive phenomenological approach based on Husserl's (1913) life world perspective to gain experience-based knowledge of the phenomenon of being care dependent. Phenomenology addresses the phenomenon of consciousness, referring to the totality of lived experiences that belong to a single person (Husserl, 1913). Phenomenon within phenomenology refers to the object as it appears to the subject (Giorgi, 1997). Giorgi' (1997) descriptive phenomenological method was used, which is clearly structured in five basic steps: collecting of verbal data, reading of the data, dividing of the data into parts, organizing and

expressing raw data into disciplinary language and expressing the structure of the phenomenon.

Before starting data collection the researchers met to disclose and write down their previous judgements about care dependence. This helped to ‘bracket’ them during analysis and to accomplish the shift from a natural attitude, in which the meaning of phenomena is taken for granted to a phenomenological attitude (Husserl, 1913). The preconceptions were as following: dependence has a negative meaning and can be experienced by patients as feelings guilty, probably because of the dominant culture of western society; illness and old age can “justify” dependency and prevent it to be absolutely negative; nurses can help to relieve the feeling of guilt, by creating caring relations, showing kindness and availability to help.

### 2.2. Sample and setting

Purposive sampling with a balance between homogeneity and maximum variation (Sandelowski, 1995) was used as sampling method. This included the selection of participants able to share their rich experience about care dependence. They were chosen with a broad range of characteristics such as age, sex, education and degree of dependence, in order to include multiple perspectives able to illustrate the complexity of the phenomenon under study. The adult inpatients were recruited from the Oncology Unit of a university hospital in Rome.

In order to be eligible participants had to fulfil the following inclusion criteria: aged 18 or above, diagnosed with advanced (metastatic or incurable) cancer, being care dependent for more than one week as judged by the nursing staff, and able to understand and to speak Italian. Exclusion criteria were: cognitive or speech impairment, excessive tiredness or pathological conditions that could prevent active participation in the interview.

The university hospital where the study took place is a 300 bed acute care hospital admitting patients both under the Italian National Health Service scheme, and privately or covered by insurance. The hospital achieved the Joint Commission International (JCI) accreditation and it is committed to offer quality nursing personalized care, by maintaining high nurse-patient ratios and using a primary care model. Patients with cancer are admitted under the Italian National Health Service, which provides them with care, treatments and examinations completely free of charge.

### 2.3. Ethics

The study was conducted in accordance with the principles of the Declaration of Helsinki (World Medical Association, 2013). Eligible patients were informed verbally and in writing about the study. It was made clear that their participation was strictly voluntary. They were also informed that the data collected would be analysed and reported ensuring confidentiality and that it would not be possible to identify in written reports those who gave individual responses. Willing patients gave their signed consent to participation in the study and to the treatment of personal data in accordance with the law. The local Ethical Committee approved the study before start (protocol number 6.13 OSS ComEt CBM).

### 2.4. Data collection

The nurse ward manager was asked to identify potential participants. Between February and June 2014 a total of 16 eligible patients were approached by two researchers, informed about the study and invited to participate. Three patients refused to participate. Thirteen patients signed the informed consent and completed the interview. Participants' dependency in Activities of Daily Living

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