QUADERNO

IL CANCRO E LA SUA COMPLESSITÀ. PRENDERSI CURA: QUESTIONI ETICHE E APPROCCI NELLA CURA DEI PAZIENTI

CANCER AND ITS COMPLEXITY. CARING: ETHICAL ISSUES AND APPROACHES IN PATIENTS' CARE

Nursing care dependency in cancer patients

La dipendenza dall'assistenza nel paziente oncologico

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Introduction. The concept of dependency is influenced by culture, philosophy and politics. In centuries of philosophical reflection dependency assumed sometimes positive, sometimes negative connotations. It configures a multidimensional phenomenon, with subjective and objective aspects. Cancer patients, with their increasing comorbidities and disabilities, can be especially care dependent, both physically and emotionally.

Contributions. Findings from qualitative studies underline the relational dimension of care dependence and the centrality of the nurse-patient relationship within the patient' experience of care dependency. The bodily dimension of care dependency is also highlighted. The dependent bodies are perceived as strange, sometimes as making difficult to recognize the person behind it. The relation with the self and with others changes with dependency, patients feel sometimes powerless, struggle to maintain control over the care received or feel concern over being burdensome to others. Receiving care from others can also be source of relieve in the struggle of being dependent, appreciated as expression of care and love, and can generate gratitude and feelings of indebtedness towards carers.

Conclusions. Nurses can play a central role in transforming patients' experience of care dependence in an acceptable and positive one thus decreasing patients suffering. Nurses' awareness of the meaning care dependency acquires in patients' perceptions, could increase their opportunity to help patients to preserve their dignity.

Key words: Care dependency, relationship, embodied person, cancer patients, nursing

Premessa. *Il concetto di dipendenza è influenzato dalla cultura, dalla filosofia e dalla politica. In secoli di riflessione filosofica esso ha assunto a volte connotazioni positive, ma più spesso negative. La dipendenza dall'assistenza si configura come un fenomeno multidimensionale, con aspetti soggettivi e oggettivi. I malati di cancro, con le loro crescenti co-morbilità e disabilità, possono essere particolarmente dipendenti dalle cure, sia fisicamente che emotivamente.*

Contributi. *I risultati di alcuni studi qualitativi sottolineano la dimensione relazionale della dipendenza dall'assistenza e la centralità del rapporto infermiere-paziente all'interno dell'esperienza di dipendenza del paziente. È evidenziata anche la dimensione corporea della dipendenza dall'assistenza. I corpi dipendenti sono percepiti come strani e a volte rendono difficile riconoscervi la persona. Il rapporto con sé e con gli altri cambia con la dipendenza, i pazienti si sentono a volte impotenti, lottano per mantenere il controllo sulle cure ricevute o sentono la preoccupazione di essere di peso per gli altri. Ricevere assistenza da altri può anche essere fonte di sollievo nella lotta dell'essere dipendente, apprezzato come espressione di cura e amore, e generare sentimenti di gratitudine e indebitamento verso chi presta le cure.*

Conclusioni. *Gli infermieri possono svolgere un ruolo fondamentale nel trasformare l'esperienza di cura della dipendenza in un'esperienza accettabile e positiva, riducendo così la sofferenza dei pazienti. Una maggiore consapevolezza del significato che la dipendenza acquisisce per i pazienti, può permettere agli infermieri di aiutarli meglio a preservare la loro dignità.*

Parole chiave: *Dipendenza dalle cure, relazione, corporeità, pazienti oncologici, assistenza infermieristica*

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Dependency: an introduction

Dependency is an extensively used yet questioned concept. It has been debated within many different disciplines ranging from sociology, psychology, anthropology, ethics and healthcare sciences. The etymology of the verb to depend and of the noun dependency relates to a physical relation in which one thing hangs from another. In the actual use dependency for sociologists has four registers of meanings. The first register is economic, which refers to an individual who depends from other persons or institutions for subsistence. The second refers to a socio-legal status, where one lacks separate legal or public identity. The third register is political, where dependency implies to be subjected to an external power. The fourth register is the moral or psychological, where a dependent person has character traits such as lack of self-command or excessive emotional needs (Fraser and Gordon, 1994).

In preindustrial society the term dependency meant subordination as a normal condition common to most people and a recognized social relation. Since the rise of industrial capitalism the meaning of dependency acquired negative connotations and was seen as defect of individual character. Thus, independence became the ideal image while dependence started being associated with a stigma. In post-industrial capitalism all usage of the term dependency became negative as avoidable and blameworthy. As Fraser and Gordon argued in "A genealogy of dependency" (1994), with capitalistic economic dependency abolished by definition, and legal and political dependency abolished by law, the remaining dependency seems to survive as the fault of individuals. Therefore dependency becomes increasingly individualized and implicit or explicit fear of dependency poses ideal independent personality as opposite to those who are dependent and thus become deviant.

Since the rationalism of Enlightenment and the consequent liberism accompanying the economic and socio-political changes within the passage from preindustrial to post-industrial society, autonomy, independence and rationality have been seen as the key characteristics of the human individual (Kittay, 1999). In this view, vulnerability and dependence are no longer considered integral parts of human life, but rather signs of imperfection of humanity (MacIntyre, 1999). Therefore, in public life dependency appears shameful and avoidable. In contrast, independence and autonomy are considered as universal goals strongly related to personal dignity by the main theories of justice (Kittay, 2011).

Besides the sociological registers of meaning described above, other kinds of dependency are health-related or physical and age related ill-health and frailty. Again, some health-related usages of dependency display negative meanings with connotation of unhealthy psychological dependency, such as Dependency Personality Disorders, or are synonyms of addiction, for instance to drugs, tobacco, Internet, gambling, pornography (Fine and Glendinning, 2005).

For some theorists of the Disabled People Movement (DPM), a very negative view of dependency may be generated also from the concept of care as one contributing to construct disability as a dependent status. In their view, disabled people receiving care live awful lives and social policy constructs them as a burden, which drains limited public resources (Hughes et al., 2005).

Some feminist theorists overcome this view of care and dependency and introduce the concept of inevitable interdependency, that implies mutual need expressed in caring behaviours and responsibilities. They highlight the universality of caring, and argue that everybody will need some kind of care at some moment in life. Thus they challenge the idea that economically independent and rational individuals will predominate in social life, while receivers and givers of care will both be considered as burdensome (Fraser, 1989). Similarly, Kittay makes a "dependency critique" as a feminist critique of the liberal view of equality. She argues that seeing society as an association of equals conceals inevitable dependencies, such as those in childhood, illness, old age and temporary or permanent disabilities. The focus on corporeal vulnerability is a central aspect of her dependency critique. Dependence and independence are put in the context of an embodied life, from birth, through development and ageing, to death. As other earlier feminists she warns against the idealization of persons as independent and fully functioning by public policies, unaware of the real experiences of people with different degrees of dependency who are therefore inevitably marginalized (Kittay, 1999).

Dependency as such is one of the defining features of human beings. Old age, illness or physical impairments can increase that dependency, but dependency itself is constitutive of human beings (Colombetti, 2013) as a consequence of the fragility of human condition (Ricoeur, 1960). Humans are frail, vulnerable and constitutively dependent not only because of their bodily, animal condition, but also of their relational nature that requires them to live and develop in relation with others (Kittay, 1999; MacIntyre, 1999). Thus, dependence is an experience that everybody has from childhood to achieve personal independence in adulthood and then return to some level of dependency during old age or illness (Levinas, 1990; MacIntyre, 1999).

Care dependency

Care dependency is a central concept for nursing, which is aimed at helping people who are no longer independent in activities of daily life to meet their basic human needs. Nursing activities are always aimed at promoting and restoring all the possible independence (Henderson, 1966; Orem, 1995; Roper et al., 2000). In particular, for Henderson (1966) the promotion of independence is the unique contribution of nursing. As she states: "Nursing is primarily helping people

(sick or well) in the performance of those activities contributing to health, or its recovery (or to a peaceful death) that they would perform unaided if they had the necessary strength, will, or knowledge. It is likewise the unique contribution of nursing to help people to be independent of such assistance as soon as possible". Therefore, nursing care dependency as underlined by Henderson is multidimensional, as composed by physical, cultural and motivational aspects. Accordingly, nurses' activities aimed to help people who lack the required strength, will or knowledge will be technical, relational and educational. Similarly, for Orem (1995) the activities of self-care are those that people perform independently throughout life to promote and maintain personal well being; thus, nursing interventions (wholly or partially compensatory, or supportive-educative interventions) are needed when an individual is unable to perform the necessary self-care activities.

Several concept analyses defined dependence as a relational concept. These definitions of dependency are in accordance with George (George, 1991, p. 178) who stated: "one cannot be simply dependent; one must be dependent on someone for something". The first concept analysis of care dependence identified it as a relational state, where dependency needs are innate and pre-exist to illness (Carnes, 1984). Then Dijkstra et al. (1998, p.144) defined 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". Lastly, Boggatz et al. (2007) defined care dependence as a "subjective, secondary need for support in the domain of care to compensate a self-care deficit". This definition does not show care dependency always as a negative condition, because people may be dependent but may feel happy and in control of the situation if their needs are met. However, a subjective definition of dependence makes it hard its application to situations of objective dependence when patients' cognitive problems might hinder the self-awareness of their need for care.

As showed above, different philosophical and sociological views attribute dissimilar meaning to the construct of dependency, positive or negative. Therefore, when a situation of dependency generates within a socio-historical context embedded in a negative view of dependency, it might be lived as a more negative experience than in a context where the vision of dependency is positive. Thus, the experience of care dependence can be strongly influenced by culture. For instance, cultural differences in the perception of care dependency were reflected in studies conducted in Egypt compared with others in European countries (Boggatz et al., 2009a; Boggatz et al., 2009b) and in Eastern compared with Western countries (Lamb, 2005). The common vision of dependency in contemporary Western culture can increase the suffering, the humiliation and helplessness of persons who experience an increase in their level of dependence for personal care (Strandberg et al., 2003).

The concept of care dependency appears multidimensional, with both subjective and objective aspects. However, its meaning still need to be fully analysed in depth, in particular among cancer patients.

Care dependency in cancer patients

A cancer diagnosis may imply important physical and psychological consequences among which sometimes is included care dependency in activities of daily life. The incidence of cancer in Europe is rising; at the same time, increasing advances in cancer treatment and a progressively ageing population contribute to reduction of overall cancer mortality (Ferlay et al., 2013). Therefore, cancer patients are more likely to experience more comorbidities, disabilities and to become in some degree care dependent (Sullivan et al., 2011).

Actually, cancer resulted a predictor of increasing dependency in residents of long-term care facilities (Calijouw et al., 2014). While dependency levels in the last year of life in non-cancer patients increased with age, they were not substantially different with age and were higher in cancer patients than older non-cancer patients (Addington-Hall et al., 1998). In addition, needing more help and dependency in personal daily activities were associated with low quality of life in elderly cancer patients (Esbensen et al., 2007; Esbensen et al., 2012).

Being care dependent on others led to feelings of inadequacy and inferiority in cancer patients within a qualitative study about the meaning of living with cancer (Siqueira et al., 2007) and was an upsetting experience that impacted daily life of persons receiving treatment for advanced breast cancer (Luoma e Hakamies-Blomqvist, 2004).

One of the main concerns of people imagining a future situation of advanced cancer resulted "Being a burden to others" (Bausewein et al., 2013) and it was a great concern also to elderly patients facing a cancer diagnosis (Esbensen et al., 2012; Esmaeli et al., 2013), for patients with advanced lung cancer (Refsgaard and Frederiksen, 2013) and for those receiving palliative care (Doumit et al., 2007). Accordingly, one of the most frequent meanings of the desire for hastened death expressed by patients with advanced cancer was that of relieving family members from the burden of care (Coyle and Sculco, 2004).

Therefore, it seems important to try to better understand what are the experiences of cancer patients who are care dependent. Qualitative methods are best suited to explore experiential meaning. Several qualitative studies have been conducted that investigated elderly Danish patients just diagnosed with cancer (Esbensen et al., 2012) or patients with advanced cancer in palliative care in Lebanon (Doumit et al., 2007) and Sweden (Eriksson and Andershed, 2008).

Patient's experience of care dependence appears as positive in some instances, and as negative in others. The study by

Eriksson and Andershed (2008) showed how care dependence might cause suffering in advanced cancer patients, with moments of respite. They described patients' strenuous journey from independence to dependence, back and forth between the struggle with dependence, and moments of acceptance and comfort in getting care from others. The feeling of respite implied patients allowing themselves to be dependent, feeling security and trust in caregivers who accepted their dependence and tried to provide the help required.

In particular, some patients perceived their body as unrecognizable, strange or shameful; it was seen as a burden because it was experienced as unknown, and as reacting differently from when patients were independent and controlled their bodies. Loss of control over their bodies was experienced as especially difficult when it regarded elimination. This situation may lead to feeling frustration and helplessness (Eriksson and Andershed, 2008). The body of the dependent person unveils physical changes that lead to changes within the whole person. Bodily changes include physical impairments that put the body at the forefront, making it socially observable. These changes show limitations in daily life that may lead to needing the help of others. On the other hand, the dependent bodies, while visible to themself and to others, make it difficult to recognize the very persons behind them, thus veiling the person. This was expressed by estrangement from one's body and by the perception of an unrecognizable body (Eriksson and Andershed, 2008).

With dependence the relation with the self and others seemed to change. In several studies patients seemed to grieve for their lost abilities. In most cases suffering seemed harder to patients when they described themselves as being very independent previously (Doumit, 2007). Patients sometimes had to strive to maintain control over the care provided to them in terms of type, timing and amount of care. When they lacked influence on the care, they felt powerlessness (Eriksson and Andershed, 2008). They also expressed the wish to be treated with respect.

The nurses' role in helping people who experience care dependency to face their new self is crucial especially in keeping the integrity of patients' personal dignity and identity. Nursing care can make patients feel welcomed and acknowledged as the persons they used to be, notwithstanding their emotional and physical reactions change. In this sense, affinity with other people, which arose within personal encounters embedded in mutual respect, common understanding and openness toward each other, could make dependency easier. When both patients and nurses could make their contribution by giving and receiving, the sense of affinity was strengthened (Eriksson e Andershed 2008).

In acute hospitals sometimes the organization of care, nursing workload and staff turnover did not allow nurses to devote much time for patients' needs. Rushed nurses could give the impression it was hard for them to give care and that they had an expectation that patients should become independent. Thus, some patients felt it was difficult asking for help, and were concerned they may deprive other patients of the care required. They were also considerate towards nurses, justified them. They also accepted caregivers' incapability and tried to overlook their shortcomings in care.

Another important aspect where nurse can make a difference is patients' feeling as a burden. Dependent patients faced the unavoidability of not being able to manage by themselves and the concern over being burdensome to others (Eriksson and Andershed, 2008). This was also reported by elderly receiving a cancer diagnosis and becoming dependent on others for activities of daily life who felt dependence as the worst consequence of living with cancer because it caused disruption in the harmony of family (Esbensen et al., 2012). Moreover, sometimes patients endured great suffering before asking for care and worried about being a burden for busy nurses who might believe they were troublesome (Eriksson and Andershed, 2008). With nurses able to recognize patient' feelings and to welcome patients' needs with caring availability, patients suffering may decrease.

Dependency could generated also feelings of gratitude and indebtedness for the care received, that was appreciated as an expression of love (Esbensen et al., 2012, Eriksson and Andershed, 2008).

Conclusion

This paper draws attention to an important topic for nursing. The nurse-patient relationship seems to play a key role on directing patients' subjective experience of dependence toward a positive or negative one. Therefore it appears essential to the meaning patients attribute to their dependency and to the outcomes of care. This provides support to the idea that the nurse-patient relationship is central to nursing and that is maybe the most effective way to influence patient health outcomes.

The experience of dependency reveals the reality of the embodied person as it implies not only a bodily experience, but also a global personal experience. Actually, the bodily dependence carries physical, emotional, cultural, social and spiritual involvement. This is especially evident among cancer patients, who represent to a great extent those aspects of vulnerability and frailty, so often forgotten and put aside by our society in order to put at the forefront models of independence and autonomy as the only goal of human existence. However, dependence, disability and vulnerability are integral parts of human beings and to ignore them means to reject a constitutive dimension of our essence (MacIntyre, 1999).

The experience of care dependency, in particular for cancer patients, can acquire multiple meanings, depending also on the cultural context and has not been fully studied. Patients' perceptions of care dependency have been explored mostly through qualitative research conducted in Northern

Europe, but the studies on the cancer population are sparse. Therefore more research is needed especially in Italian cancer patients both in hospital and in palliative care settings. Given the relational nature of care dependency, also studies addressing the nurses' perspectives could help to draw a more complete picture. These studies could add knowledge on how cancer patients live with dependency.

Nurses' awareness of the meaning care dependency acquires in patients' perceptions, could increase their opportunity to understand how they can help patients to preserve their dignity, by engaging in significant personal relationship, seeing always the persons hidden behind the dependent bodies, welcoming and encouraging patients to ask for help, and trying to maintain all the possible control over the care situation.

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