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ORIGINAL ARTICLE

Finding meaning in life: an exploration on the experiences with dependence on care of patients with advanced cancer and nurses caring for them

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Abstract

Purpose Patients with advanced cancer are likely to face increasing levels of care dependence. Adult patients who become care dependent on others can experience this condition as one of suffering and humiliation. The nurse-patient relationship plays a key role in the experience of dependence. Understanding patients' and nurses' perceptions of care dependence is crucial to addressing the impact it has on the lives of both. The aim of this study is to explore the experiences of patients with cancer and nurses caring for them.

Methods A multicentre qualitative study was conducted in Italy using semi-structured interviews with patients with advanced cancer admitted to 3 hospitals, and 9 focus groups with nurses working in oncology wards of 2 hospitals. Data were analysed with inductive content analysis.

Results Thirty-two patients and 44 nurses participated in the study. Three common themes were identified: within dependence, the relationship is a lifeline; dependence is influenced by internal and external factors and dependence generates changes. Dependence impacts on patients' and nurses' lives and implies a process of personal maturing for both. Patients learn the humility to ask for help by exposing their vulnerability. Nurses become aware that a trusting relationship helps patients to accept dependence, and they learn to self-transcend in order to build it.

Conclusions Striving to build positive relationships implies a change in nurses' and patients' lives. In this way, they come to understand important aspects of life and find meaning in difficult situations. Further studies should explore also homecare settings and patients' families.

Keywords Care dependence · Focus groups · Interview · Neoplasms · Nurses · Qualitative research

Introduction

Recent advances in cancer diagnosis and treatment are achieving greater survival rates. At the same time, the incidence and burden of cancer is growing as the population ages [1, 2]. These demographic and epidemiological shifts mean that an increasing proportion of patients with cancer will be older adults, who will probably suffer from comorbidities and disabilities [3]. Therefore, patients with cancer will be more likely to survive, to grow older and to face some level of care dependence [4]. Human beings are characterized by relationality [5] and therefore they are constitutively dependent on one another [6]. Humans need relationships with others to be recognized as valuable persons, to develop their personal identity, to feel loved and to live meaningful lives [7]. Therefore, dependence is constant throughout life, as it is also strictly linked to the bodily, vulnerable human condition [8].

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However, dependence is considered more obvious in early childhood and advanced age when people owe their physical survival to others [7, 9]. A condition of severe illness can bring dependence to the fore, making people more conscious of it [10]. In contemporary individualistic societies, which place great value on independence and self-sufficiency, being dependent on others is considered as a loss of autonomy and freedom and might be stigmatized [11]. This negative view can increase the suffering and humiliation of adult people who, after achieving independence in the activities of daily life, suffer a regression to care dependence because of severe health conditions or disabilities [12].

In order to be able to help patients coping and living with care dependence, health professionals must be aware of the patients' perceptions of needing care from others. Several qualitative studies have been conducted to explore patients' experiences with care dependence. A meta-synthesis showed that the relationship between patients and nurses caring for them played a key role in the overall patient experience of dependence [13]. The perceptions of patients with cancer were investigated only by four qualitative studies conducted in palliative care or in acute care hospitals [14–17]. Dependence was a great concern for patients with cancer in different contexts of care because they felt they were a burden to others [14, 15]; moreover, it could change patients' relationships with others and with their own body, which was perceived as shameful and strange [16]. Despite such negative feelings, dependent patients with cancer might have moments of respite in which dependence was accepted [15], they learnt to cope with it, and discovered new meanings in life [17].

Care dependence is a key concept for nursing, one of whose aims is to take care of people who become dependent on care [18, 19]. However, the aforementioned social denigration of patients' dependence also affects those who provide dependent care, and caregivers' work becomes invisible and valueless [8]. Caring for dependent patients can be fraught with difficulties and therefore can influence nurses' emotional and physical health [20]. Every individual nurse can attribute a subjective meaning to the care situation. Understanding nurses' perceptions of care dependence is crucial to raising awareness of the importance of their relationship with dependent patients, and of the impact they can have on the patients' lives as well as their own [20]. Several quantitative studies have focused on measuring care dependence, for instance to determine the required level of nurse staffing [21]. In contrast, qualitative literature aimed at deepening the knowledge of care dependence by exploring nurses' experiences, is still scarce. Strandberg and Jansson [20] conducted a study on nurses' perceptions of care dependence in medical and surgical wards at a large county hospital. They showed dependence as burdensome for both patients and nurses; in particular, it was shown as evoking feelings of guilt and insufficiency in nurses, who found it hard taking care of such patients [20]. To our knowledge, no studies have been conducted about oncology nurses' experiences of care dependence.

As dependence on care has a strong relational connotation [13], it is crucial to explore the perspectives of both patient and nurse to get a wider view of the phenomenon. Therefore, this study aims at exploring the experiences of patients with advanced cancer who are care dependent and of the nurses caring for them.

Methods

Design

This is a multicentre qualitative study using inductive content analysis, which is content-sensitive and facilitates the production of core constructs from textual data [22].

Sample and setting

Patients were recruited in the oncology wards of three hospitals located in the Italian cities of Rome, Reggio Emilia and Florence. A purposive sampling was performed to include patients able to share rich experiences of care dependence, and with heterogeneous sociodemographic characteristics. The inclusion criteria for patients were (1) Italian speaking, (2) aged 18 or over, (3) confirmed diagnoses of any type of advanced cancer (metastatic or incurable), (4) experience of care dependence measured with the "Care Dependency Scale" (Italian version) with a score ≤ 68, and (5) Eastern Cooperative Oncology Group (ECOG) Classification ≤ 3 or Karnofsky $\geq 40\%$.

Nurses working in the oncology wards of two hospitals in Rome and with at least 1 year of experience taking care of dependent patients with advanced cancer were invited to participate.

Ethics

The study was approved by the Ethical Committee of the leading centre (Prot. 6.13 OSS.) and was conducted in accordance with the principles of the Declaration of Helsinki [23]. Researchers provided eligible patients and nurses with verbal and written information about the aim of the study, data collection and data confidentiality. Willing participants signed a written form giving consent to study participation and to handling of personal data in accordance with national law.

Data collection

Trained researchers conducted semi-structured interviews with patients and focus groups with nurses, in Italian, between March 2015 and May 2016. The interview was flexible, and

adapted to the needs of vulnerable populations such as patients with advanced cancer, facilitating interaction with participants [24]. Focus groups were employed with nurses in order to obtain rich data about shared experiences and to elicit opinions that might not have surfaced during individual interviews [25]. A research assistant acted as co-facilitator during focus groups. To promote thought-sharing, some open questions were used (Table 1) such as the following: "What is dependence in your opinion?" and "What does dependence on care mean for you?". Participants were encouraged to talk freely and to narrate their experience of dependence. Interviews and group discussions were audio-recorded and transcribed verbatim.

Data analysis

Patients' and nurses' data were analysed separately in a first phase and then joined together in a second phase. During the first phase, two researchers independently engaged for a long time with the transcripts. They made notes and added headings within the texts to freely generate categories using inductive content analysis [22]. In the second phase, all the categories coming from both sources were compared and grouped together as subthemes. Through subsequent abstraction, broader themes were generated from similar subthemes. Finally, a third researcher independently checked consistency with the original transcripts of the categories, subthemes and themes generated throughout the whole process of analysis.

Rigour

Researchers used several strategies to achieve trustworthiness [26, 27]. They assumed a non-judgmental attitude during both interviews and focus groups. To give objectivity to the study, researchers followed the five steps of the semi-structured interviews guide developed by Kallio et al. [24]. As they were not involved in care, they could objectify what had emerged during the interviews with patients. To increase credibility, the data were recorded, transcribed verbatim and analysed through qualitative content analysis [22]. The methods used for data collection and analysis were clearly documented, ensuring dependability. The researchers who performed the analysis shared the findings with the others to increase confirmability. A description of the context characteristics was provided in order to allow transferability.

Findings

Sample

The patient sample included 32 participants, 17 men and 15 women (10 in Rome, 12 in Florence and 10 in Reggio Emilia), between 41 and 80 years old. Their educational level ranged from primary ($n = 9$), intermediate ($n = 6$), secondary ($n = 11$), and university ($n = 5$) to post-graduation ($n = 1$). Individual interviews lasted from 10 to 50 min.

Nine focus groups were held (four in hospital A and five in hospital B) with 44 nurses working in oncology (23 in hospital A and 21 in hospital B), nine of whom were male. Their age varied between 23 and 56 years old. Five nurses, all of them working in hospital A, had attended a postgraduate course in oncology nursing. The number of participants ranged from 4 to 8 per group. Each focus group session lasted between 30 and 50 min.

Content analysis

The analysis of the whole dataset generated three themes and eight subthemes (Table 2), which are presented as follows along with some excerpts from the transcripts supporting them. Confidentiality will be ensured for specific quotes by using an alpha numeric identifier for patients and focus groups. Line numbers will be reported if appropriate.

Within dependence, the relationship is a lifeline

For patients, the relationship is at the basis of dependence when they realize they are in need. As one participant discloses: "There are moments in life when you have just to trust someone" (PZ6). Patients wish to have someone close. Positive relationships with nurses make them feel better and safe: "I feel safe when the professionals are kind and affectionate towards me" (PZ8). Nurses agree with patients' remarks: "The relationship is fundamental for the patient. For this reason, I'd say it's unavoidable… The patient needs it"

Table 1 Topic guides

Questions for patient's interviews	What is care dependence in your opinion?
	What does dependence on care mean for you?
	How do you feel being care dependent?
Questions for focus group with nurses	What is care dependence in your opinion?
	What does it mean for you to take care of dependent patients?
	How do you feel taking care of dependent patients?

Table 2 Overall findings

Subthemes	Themes
1) Nurses' closeness and competence make patients feel safer	Within dependence, the relationship is a lifeline
2) Patients look for selective relationships	
3) Dependence is reciprocal	
Dependence arouses emotions	Dependence is influenced by internal and external factors
Patients suffer from constraints in hospital	
The powerlessness of the body causes derangement of life	Dependence generates changes
The quality of relationships changes	
Dependence impacts on patients' and nurses' lives	

(FA2, 213–214). Nurses call the patients' wish for closeness *emotional dependence*: "There is an emotional dependence: sometimes when patients push the call button there is not a real need: they are only finding an excuse for having you close" (FA1, 52–56).

Dependent patients with cancer are aware that nurses need several specific skills to care for them. They note, for instance: "In addition to competences they need to have *a strong stomach* to carry out this work…" (PX6). Nurses add their views on the reasons why their competence is important to patients: "If we answer to their questions showing ability and competence, they feel safer" (FA3, 276). Nurses also disclose that patients tend to link with a particular nurse in the team and to look for his/her attention. They note that the patient tries "to tighten a precise bond and to create a selective relationship" (FB1, 143,172). They illustrate this by graphically explaining: "Twenty minutes is enough, once you have talked with them, you become a lifeline" (FA1, 296–297). Nurses underline that dependence involves not only patients: "Dependence becomes reciprocal because it's a giving and a receiving" (FB4, 101–102).

Dependence is influenced by internal and external factors

Patient participants underline their difficulty in accepting the condition of dependence: "It's something that destroys you" (PX10). Others strive to react against dependence: "I'll do everything possible to get out from this situation!" (PY7). Nurses understand patients' feelings and can contribute to change their moods: "Just a glance, a smile, and already they calm down" (FA3, 31).

Patients' suffering is also due to hospitalization and they complain: "Constraints: everyday life in my home is broken by hospital" (PX5). The patient's family plays a crucial role in the experience of dependence: "It's normal, you want the family around you" (PY2). Nurses agree with patients' accounts: "Lack of privacy, schedule change and constraints, sharing the room with another patient..." (FB2, 85–86).

The overload of activities seems to be a great obstacle for nurses in caring for dependent patients. Participants in the discussion disclose: "Sometimes we make them dependent as we don't have time for patient education" (FA1, 277), and "I feel quite frustrated as I cannot dedicate to patients the time I'd like" (FA1, 127). Nurses underline the need for resources that should be available to professionals to reduce workload, and to stimulate patients to recover their autonomy.

Dependence generates changes

Patients regret their past activities and express the powerlessness of their body. They understand that their own life is changed: "Life is completely upset. Dependence impacts strongly on quality of life" (PX5). Also, the relationships with nurses require changes in the patients' behaviours. Patients underline that "When you understand that you cannot do things all by yourself anymore you have to ask for help, to rely on someone" (PX3). Similarly, they express the need to start a process of adaptation to their situation and to the people caring for them, and report: "Becoming aware of needing somebody's help is a path to maturity" (PZ3).

Nurses' discussions point out that learning to ask for help requires humility and courage on the part of patients: "They need some humility! (They need) to say: 'Yes, I need help'. Some little dependence is good" (FA1, 351–352). Nurses realize that dependence generates important changes in patients' lives: "Dependence somewhat strengthens relationships" (FA1, 341–353). They also note that dependence generates changes in their own lives: "This being like a 'sponge' changes you. I realize I'm a different person" (FA3, 135–140). Some nurses define caring for dependent patients as a "heavy experience" (FB1, 200–203) that makes them feel "psychologically destroyed" (FB1, 267). Participants share being afraid to fall into cynicism or emotional detachment: "Well, there is this fear because, you say, after three years you have become so detached. After twenty years what will you be like?" (FA3, 193–195).

Discussion

The aim of this study was to explore the phenomenon of dependence on care from the perspectives of both patients

with cancer and nurses. Although the importance of the relationship with nurses for care dependent patients is not a new finding [13, 28], the added value of this study is that when the relationship regards patients with cancer and nurses caring for them, it becomes a lifeline. Patients build their own mental image of the nurses, choosing one of them as their reference-point [29]. They look for safety [30], comfort and proximity [17]. Technical skills are secondary: patients have to feel that the nurse is giving them genuine care rather than performing competently [29]. From the perspective of Swanson's caring theory [31], it seems that "being with" is fundamental for dependent patients with cancer and nurses caring for them rather than "doing for".

Another new and interesting finding is that caring in dependence involves a profound change of the nurses' mind. They have to be ready to give themselves to patients in order to be able to accept their opinions even when they conflict with their own wishes to care for them, and therefore to promote compassion by "mindful practice" [32]. This way of giving themselves to patients in order to be able to go beyond their own personal limits and views—that is self-transcendence—to establish positive connections with dependent patients is crucial for caring, in accordance with a previous study conducted with palliative care nurses [33]. Nurses in this study expressed a wish to be present in crucial moments of patients' lives, and described their involvement in the relationship with the patients as itself a kind of dependence [30].

Moreover, nurses in this study show awareness that care dependence can be associated to burnout. They are afraid of falling into cynicism or emotional detachment as manifestations of burnout [34]. Self-transcendence can save nurses from this risk [35], and is critical for nurses to understand the patients' negative feelings, such as sense of insufficiency and of being a burden to others [12, 33] that are common in dependent patients. Thank to self-transcendence, nurses react to patients' feelings by adapting their care and behaviours in order to help them to experience their condition peacefully.

Feeling the vulnerability of their own body has an influence on the quality of patients' lives. In individualistic societies that greatly value self-sufficiency and believe in the myth of the "self-made man", people can find it hard having to ask for help and consenting to receive it. In fact patients who receive something want to requite it in some way, because feeling indebted to someone makes them feel guilty [36]. According to Løgstrup "Patients are reluctant to verbalize their need for care because it would expose their vulnerability" [37]. The powerlessness of the body causes strong psychological and social changes in patients [13], who can enter upon a path to personal maturity by accepting their condition, putting aside pride and learning to ask for help [13, 17]. This requires humility, a virtue that is described as unpretentious openness, honest self-disclosure, avoidance of arrogance, and modulation of self-interest [38]. Humility helps a person to have a realistic view of the self and to stay open to reality, including human finitude and dependence on others [39].

MacIntyre [7] points out that there would be a really "human" society when the vulnerability of human beings is considered as innate, and when the acknowledgement of dependence generates virtues enabling people to flourish by giving and receiving according to their interdependence. Patients' exposed vulnerability requires nurses to exercise their own practice with moral responsibility regarding the building of trust and the use of power inherent in the asymmetric care relationship [40]. The creation of trusting care relationships with patients is a great commitment for nurses, as powerful cultural barriers in western society discourage positive experiences of care relationships. The feminist ethics of care point to interdependence as an essential human feature, and to attention to the other's needs as the true model of ethical interaction, rather than that of reciprocal exchange between equals [8]. Nurses have to work on themselves in the relationship with the patient with an ethically based intentional mindfulness [37]. Patients who are cared for by nurses in this way do not feel violated, and trust nurses [40].

The efforts made by dependent patients and nurses to build positive relationships reveal a profound change in their own lives that directs them to a new understanding of the important things in life [13]. Frankl's "will to meaning" [41] is a powerful motivating force for human beings. Knowing that there is a meaning in one's life helps one to survive even in the worst conditions. Therefore, caring relationships built on trust can help finding meaning in difficult situations [41]. This is true for patients as well as for nurses: the unique relationship with patients may help nurses to find meaning in the immediate caregiving situation [20].

Limitations

The study has some limitations. Only inpatients were included; therefore, the perspectives of patients cared for at home were not explored. Furthermore, studies on specific populations of older adults with cancer [42] could provide interesting insights on care dependence in this demographic and epidemiologic transition era. Participants' discussions often mentioned the patient's family, who seem to have a role in their experience of dependence. However, this study did not take into account the views of families on patient care dependence, and future research should explore it. Nurses were only recruited from two hospitals in Rome for the focus groups so we were not able to report if their views differed from the other two Italian cities.

Implications for practice

Nurses caring for patients with cancer should be aware that establishing trusting relationships with dependent patients is fundamental in order to enable them to cope with dependence. Care dependence requires personal adaptation from both the cancer patient and the nurse; this will allow them to find new meanings in their lives in dependence and in their jobs, respectively.

To recognize the symptoms of burnout and to prevent excessive involvement and occupational stress, institutions should use the strategies available to avoid burnout [43]. By balancing the attempt to establish empathetic engagement and setting appropriate emotional boundaries [44], nurses can find meaning in their job thanks to psychological well-being and hope [45].

Conclusions

Thanks to relationships patients and nurses can add profound meanings to their lives by enriching them with significant experiences. This study is meaningful due to the importance given to both patients' and nurses' perceptions of dependence, which allowed researchers to enrich the available knowledge about this phenomenon by adding the nurses' point of view in connection with the patients'. The unique and authentic relationship patients wish to build when considering nurses as lifelines, lead to their being well known by nurses. This implies a great commitment for nurses and brings them to an awareness that their relationship with patients can help them to attach deep meanings to their caregiving and life. To further broaden knowledge of the phenomenon of dependence, it would be useful to conduct studies in homecare settings and to explore the point of view of patients' families.

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All authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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