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RESEARCH ARTICLE

The Perception of Nurse Case Care Managers About the Needs of Cancer Patients

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Abstract

Background and aim. Several studies in the literature state that cancer patients show unmet needs despite standard care. The aim of the study was to understand the perceptions of oncology case care managers regarding the met or unmet needs of patients and relatives.

Methods The study used a qualitative approach through a semi-structured interview. Twenty Case Care Manager (CCM) nurse practitioners performing their function in four AUSLs in Northern, Central-Northern and Central Italy were recruited and selected on a convenience criterion. The study ran from April 2021 to February 2022.

Results: It emerges that numerous needs are not always met and that dysfunctionally affects the quality of life of cancer patients. These include information, emotional, psychological and social needs. Feelings of fear, distress, anxiety and depression often accompany them. These are complex needs which are difficult to answer. Case care managers have shown themselves to be able to recognise the needs. These findings underscore the urgent need to recognise and address the complex needs of cancer patients and their relatives. This study serves as a call to action, urging the healthcare community to strive for comprehensive solutions to these pressing issues.

Conclusion: CCMs, being a stable reference point for patients and their families, acknowledge that they create a relationship of trust with patients, with a positive impact on their quality of life.

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Keyword: cancer patient, unmet needs, Case Care Manager, role, qualitative research, interview.

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1. Introduction

Considering the literature review and the results of a recent study conducted on cancer patients (Foà C et al., 2020), numerous bio-psycho-socio-relational needs that are not always satisfied and that dysfunctionally affect the quality of life emerge.

Among those most unmet are emotional and psychological needs.

These are mainly identity-relational changes and are often accompanied by feelings of fear, anxiety and depression, which are often difficult to recognise and express.

The literature documents that these needs do not all surface at the same time but arise according to the stage of the illness in which the patient is in, according to age, culture, and country of residence, in consideration of free care and quality of health services (Ahern et al., 2015). The presence of unmet needs also affects quality of life and perceptions of quality of care (Miyashita et al., 2015).

These findings suggest that more attention should be paid to understanding these needs and identifying obstacles to their fulfilment.

1.1. Living with illness and the needs of the cancer patient

The journey of a person who falls ill with cancer is often uncertain. It involves alternating phases where illness, loss and stressful situations to cope with can put the person's psycho-physical well-being at stake.

Adaptation to the disease and the acquisition of awareness are processes that change over time and depend on various factors (social, cognitive, environmental). With time and the help of specialised personnel, initial reactions aimed at passivity and abandonment may be replaced by more adaptive, conscious, and mature modes (Buton et al., 2020).

Three aspects cannot be neglected in cancer pathology: - severity; - chronicity and the threat of death.

Rainbird et al. (2009) point out that the areas of greatest need are psychological-emotional and communication-informational. Patients report difficulty managing their needs, and many want help identifying and managing them (Fitch, 2012).

The primary unmet needs include psychological support, medical care and treatment equality, continuity of care in the hospital and at home, and information on diagnosis and treatment. (Foà et al., 2014)



Although providing information to patients is considered to be a fundamental support element in oncology for all stages of disease (Husson et al., 2011; Ugalde et al., 2012), the need for information very often remains unmet (Harrison et al., 2009; Low, Chen Ee, et al., 2024).

Patients express their needs differently according to age and level of education (Hart et al., 2022).

A discrepancy between users' and professionals' needs has also been observed (Tamburini et al., 2000; Evans Webb, 2021).

Very often, the needs perceived by those being cared for do not coincide with what, on the other hand, is perceived by health professionals: many factors, e.g. differences in personality, social class and culture (Ayvat et al., 2023), can create barriers that prevent the sick person from expressing their needs. In addition, professionals are often unwilling to give people the full range of information about them, as it may be difficult to disclose certain information, particularly that concerning prognosis (Francis et al., 2023).

Various studies show that users most often report psychological-emotional (Willems et al., 2015; Fang et al., 2018) and communicative (Miyashita et al., 2015; Tresher et al., 2019) needs. The former include feelings of sadness, anxiety, boredom, fear, anxiety, and self-esteem (Fitch et al., 2012). The second includes insufficient effective and sensitive communication and listening (Soldini., 2017).

Among the primary psychological needs of the cancer user is the need for acceptance, regardless of mood, social relationships and appearance—acceptance of one's physical changes, or rather self-image (Fitch, 2012).

Attention to these needs and related interventions serve to help the user rediscover the value and meaning of things to find a sense of self even when the disease, with its progressive dependence and disability, makes this difficult (Martino, 2016).

1.2. The role and functions of the nurse case-care manager (NCCM)

The NCCM manages each case individually, "works to ensure that clients receive appropriate resources in a timely and cost-effective manner and ensures continuity of care" (Bertuol et al., 2020). Thus, one of his goals is "to reduce the use of scarce and costly resources and to improve the safety and quality of care" (Tahan et al., 2020a; b).

He or she must bring, like any other figure in the team, his or her own knowledge and skills, "abilities, functions, tasks, competencies and role responsibilities, according to the position or title that each person holds" in the organisation of care."(Tahan et al., 2020a; b) Thus, he or she must be able to assess and manage the client's needs and evaluate an appropriate care plan with him or her. The CCM, therefore, performs managerial and organisational functions, taking care of the patient and the family along the illness pathway, and clinical, relational and educational functions, providing competent responses to the bio-psycho-social and existential needs of the ill person and family members, paying particular attention to establishing effective and active listening relationships with the client. Moreover, the CCM actively collaborates with the care team, constituting an important reference point for the person, family, and other professionals.



(Garnett et al., 2020).

2. Methods

Aims

The study aimed to understand the perceptions of oncology case care managers regarding the needs met or not met by patients and their relatives.

Design and method

The study used a qualitative approach through the semi-structured interview instrument. The study report followed Consolidated criteria for reporting qualitative research (COREQ) checklist for interviews and focus groups (Tong, 2007)

Participants

Twenty NCCM nurse practitioners performing their functions in four regions of Northern and Central Italy were recruited and selected according to a convenience criterion.

Setting

The settings chosen to carry out the interviews were the oncology operating units where the different NCCMs worked.

Data collection

The research team emailed the heads of the facilities involved to inform them about the study's objectives and the type of collaboration required. Participants were selected based on their voluntary participation in the research. The research team emailed participating professionals, and a date and place were shared for a semi-structured interview. The study took place from April 2021 to February 2022.

Tools

The semi-structured interview lasted approximately 40 minutes.

Specifically, it aimed to investigate 4 areas (Table 1).

Table 1. Interview areas



Interview areas	Examples of questions
1. Case Care Manager training	How long have you been a Case Care Manager? What kind of training have you had?
2. Patient reception	What do you pay attention to when welcoming your client?
3. The needs of the assisted person	In your opinion, what are the needs most frequently encountered by the patients you care for? Which patient and family needs do you manage to meet? Which ones do you not?
4. Team work	How do you evaluate the teamwork you are involved in? What strategies do you implement to foster teamwork?

Data analysis

The interviews were audio-recorded after requesting written consent from the participants. Once the interview was conducted, it was anonymised by assigning a progressive numerical code. Thematic analysis of the interviews was then carried out according to Braun and Clarke's (2006; 2021) methodology. Two researchers independently analysed the interviews and compared the results, seeking consensus. In the event of a disagreement, they requested the intervention of a third researcher. Thematic analysis, according to Braun and Clarke, involves reading the text in its entirety, annotating the essential elements, and then identifying the relevant units of meaning, which are then classified into sub-themes and fundamental themes.

3. Results

Description of participants

20 oncology pathway case managers participated in the research, of whom 17 were women (85%) and 3 were men (15%). They were all nurse case care managers (100%).

The length of service with the position of case manager ranged from 1 year to 15 years: 14 participants had the position from 2015 to 2020 (70%), while 6 participants had the position from 2006 to 2013 (30%).

Of the 20 respondents, only 5 (25%) are also economically tenured, while the other 15 (75%) perform the function of NCCM without any economic recognition. Table 2 shows the socio-anagraphic characteristics of the participants.

Table 2. Characteristics of the participants



Characteristics	Frequencies and rates
Gender	
Male	3 (15%)
Female	17 (85%)
Profession	
Nurse	20 (100%)
Role	
Case Care Manager	20 (100%)
Oncological Operating Unit	
Breast Unit	3 (15%)
Haematology	2 (10%)
Dermatology	2 (10%)
Oncological Clinical Pathways	4 (20%)
Palliative care	1 (5%)
Otolaryngology	1 (5%)
Endocrinology	1 (5%)
Gynaecology	1 (5%)
Orthopaedia	1 (5%)
Urology	1 (5%)
Thoracic surgery	1 (5%)
Hepatobiliary surgery	1 (5%)
Oncological day surgery	1 (5%)

The main themes identified were: (i) training of CCMs; (ii) management of care pathways; (iii) reception (iv) patients' needs

i. Training of CCMs

With regard to educational qualification, 19 respondents (95 %) have obtained at least one Master's degree. Of the latter, 4 (20%) had obtained 2 postgraduate Master's degrees and 1 Master's degree, 1 (5%) had obtained 2 postgraduate Master's degrees, 2 (10%) had obtained 1 postgraduate Master's degree and 1 (5%) had obtained no postgraduate Master's degree.

Of the respondents' educational qualifications, 8 obtained a 3-year course in psycho-oncology and 1 participant obtained a PhD in nursing and public health.

It is striking that only 5 (25%) ICCM participants have a recognised function assignment from both a contractual and a role perspective. Participants report:

"[I got a Master's degree in humanistic counselling and it was a great achievement for me because it helped me so



much [...] it gave me tools that are very useful in interviewing, in being in relationship with those who are going through a time of illness]" (Int. 5).

[...] specifically regarding the ICCM nurse I did short training courses within the institute [...]"

ii. Management of care pathways

The majority of ICCMs (65%) take charge of the patient throughout the entire therapeutic and care pathway. In particular, 4 professionals (20%) stated that patient care begins during the communication of the diagnosis, and then continues until follow-up. They state in fact:

"[basically I am present during the whole communication phase from the diagnosis, So the first contact starts and the taking in charge begins]" (Int. 5).

Two professionals (10%) stated that their caring begins in the pre-hospitalisation phase and continues until discharge, with education in the use of specific devices.

"[the ostomised person is taken in charge in the pre-hospitalisation phase where the interview and the ostomy positioning drawing is carried out, which is followed by education on the management of the ostomy to the person and the caregiver throughout the hospital stay] "(Int. 9).

Some professionals (5%) take charge of the patient at an advanced stage of illness and carry out a cognitive interview in the setting (home, hospital or facility) where the patient is, explaining what palliative care is about. They then propose the most appropriate setting (hospice or home palliative care) according to the clinical condition at that time.

All professionals (100 %) stated that they take care of organising the whole diagnostic process (e.g. blood tests, CT scans), avoiding unnecessary waste of time, double examinations and disorientation in patients already struggling with the disease.

'[I think the great value is [...] that they acquire this passage: "you don't need to look [...] come to me and I will help you with all your problems, your questions, your fears]' (Int. 5).

Eight professionals (40%) stated that they are always present at all multidisciplinary team meetings and act as coordinators between all figures involved in the patient's care pathway.

iii. Reception

All professionals (100%) expressed the need to establish a good therapeutic alliance with the user through and during the first interviews. In particular, they dwell on the emotional, value, understanding and listening level.



25% of the interviewed NCCMs emphasise the importance of 'giving information and not leaving people in uncertainty and lack of information" (Int. 1) and of providing attention [to the aspect of understanding]" (Int. 13).

Nine NCCM (45%) emphasised that these aspects are especially relevant during the reception phase, trying to create a climate of trust. One tries to use [simpler language suitable for the person]" (Int. 10), so that the message one wants to convey is [short, clear, coherent]" (Int. 16).

Some NCCM emphasise that the first interviews are important to establish a good relationship.

Three professionals (15%) highlight the importance of active listening also in relation to the fact that patients often identify the NCCM as the reference point that can help them when they are unable to understand the communications of the professionals of the multi-professional team. "[the NCCM plays a fundamental role as facilitator and mediator, so that the person's pathway is "peaceful?". (Int. 1)

In the theme of welcome, three sub-themes are highlighted: (i) The emotional experience of the person; (ii) Managing silence; (iii) Managing one's emotions.

iii.1. The emotional experience of the person

A central aspect is the emotional experience of the person during the course. Attention is paid to the person, to the emotional aspects that emerge, such as [fear, needs] (Int. 15) and to the awareness that the person has of his or her illness pathway: [It is never assumed that the patient is aware of the pathway that has been activated (Int. 4)

Nine NCCMs (45%) agree on the importance of welcoming emotions, in order to facilitate awareness and recognition of needs: "[if he is anxious, if he is silent, if there is openness to dialogue, if he is calm, if he is worried]"(Int. 11) or if there is "[fear with respect to the illness [...] fear of not being able to be the same as before, of not being accepted by other's [Int. 9).

It is important for the NCCM to be aware that emotions, such as anger and grief, if not recognised and managed, can have negative effects on health and relationships. Active, empathic listening enables understanding and facilitates recognition of underlying needs, meanings and emotions. All the NCCMs interviewed (100%) agree.

"The professional puts the emphasis on BEING in what the person brings. Taking in so many questions related to fear. It is important to listen to what comes with interest and without judgement. This moment is precious and lays the foundations for a relationship of trust, which supports the person in his or her care journey' (Int. 5).

"[Attention is paid not only to what he says, but also to how he says it. Attention is paid to the gaze, eye contact, posture]" (Int. 15).

"[The patient says everything is fine, but has a terrified look on his face. The ICCM tries to pick up on these inconsistencies and emphasises the strengths, staying on a plane of reality... giving a rationality to things]" (Int. 9).



iii.2. Managing silence

Two NCCMs (10%) dwell on the importance of managing silence, as a moment of sharing suffering, but also point out that it is difficult to welcome and support. Both give this moment a meaning of authentic acceptance.

"[Attention to the 'management of silence] (Int. 19) as a moment of great value and respect for the person. It is powerful not to have to fill the moment of silence... it should be left as it is. What emerges is a great awareness of the importance of being in the relationship "in the here and now", without doing anything but being there respecting what the other brings, even silence, to which the NCCM gives a profound meaning of acceptance, "[acceptance of suffering and absence of judgement, acceptance of the other for what he or she is]" (Int. 5)

"[giving importance to the here and now, doing nothing but being there respecting what the other brings, even silence. Being in the moment the person is experiencing]" (Int. 18).

iii.3. Managing one's emotions.

Three NCCMs (15%) emphasise the importance of recognising one's own emotions in order to be able to enter the other's emotional world and to effectively support a helping relationship, [to avoid identification with the patient, but instead to be able to be empathic [...] (Int. 17).

An NCCM (5%) emphasises the importance for helping relationship professionals to undertake their own personal journey. He/she states:

"[...], if we have not solved our problems, our discomforts, we will never be able to be in a healthy helping relationship; because being in contact with the experience of illness, which involves the patient's personal, family, work, social sphere inevitably also stresses the professional. If this is not able to stay with the emotions that come from the other side to overwhelm you, you inevitably get invaded [...]" (Int. 5).

The CMCs pay attention to the human dimension of suffering and pain that is shared by all human beings, but even more so by the staff working in helping relationships: [we cannot bear the pain, the fatigue that comes with the job]"(Int. 5).

iv. The Needs of the Cancer Patient

With regard to the patient's needs, the ICCMs state the importance of paying"[...] attention to accommodating physical, psychological and social needs prior to taking charge [...]" (Int. 19)

"[...] trying to get to know the patient, to understand what needs are related to the person and the achievement of his or her personal goals, not only related to the disease [...]" (Int. 20)

"[...] pay attention to the patient's age, gender, clinical question, cultural level, whether he/she is accompanied and



by whom, in order to be clearer and better respond to needs [...]" (Int. 14).

iv.1. Perceived needs as satisfied

About the nature of needs, 40% of the CCMs pointed out that patients express a need to be reassured "[to have] the certainty that there is someone there to look after them, that they are not abandoned to their fate and perhaps the older population has a need to feel accompanied [...]" (Int. 5).

Twenty-five per cent of the interviewees stated that patients express a need to know, to be informed about their disease: " [they] have a great need to know what they are up against because they have to organise themselves [...] to know what happens next [...]" (Int. 5).

The CCMs state that patients who are increasingly elderly have increasing social needs, such as not feeling alone and having someone [accompany them to treatment] (Int. 7), and this becomes an increasingly difficult need to satisfy, even despite the intervention of social workers.

iv.2. Perceived needs not met

Some CCMs speculate that some needs may remain 'implicit' and that practitioners seek to understand and express: "
[sometimes implicitly are certainly those to be reassured and therefore to have reference persons (Int. 12) and to have a reference figure [to be contacted for any reason (Int. 6).

The CCMs perceive that patients, although not always asking openly, are very concerned about everything that will await them: [timing and diagnosis] (Int.19), and they want to be reassured about the dates of appointments because they are afraid of wasting time]" (Int. 14). Again, very concrete problems: "[the therapies that must be carried out [...] and the surgical procedures]" (Int.17).

On several occasions patients would need information [which they sometimes do not have the courage to ask the figure of the doctor] (Int. 20).

Other needs that are often underestimated or not expressed are related to the acceptance of physical changes related to the disease; The person is often afraid of losing their autonomy, not recovering their daily life and feeling heavy for family members.

The CCMs recognise that patients become increasingly dependent during illness, even when they could maintain some essential autonomy. They feel that supporting the need to maintain autonomy on the part of the patient is fundamental: "[It is important that the message is conveyed to the person that he or she will be able to become independent and return to a life of satisfaction]" (Int. 9).

The last but not least are socio-economic needs; many patients are concerned about their family members and the expenses related to the disease. Many are disoriented before the bureaucracy necessary for the obtaining of the benefits provided by the law and how to obtain exemptions from health care.



The CCM states that patients highlight the need for clarity and simplicity, for listening, for continuity of care is no less important than having the certainty to survive "[to live, they want to live! The greatest need is precisely this, security in living|" (Int. 18).

Faced with these needs, often not clearly expressed but recognized by experienced professionals who follow people so closely, CCMs have different views on whether or not they are able to provide more competent and effective responses.

Only 35% of the NCCMs have expressed that they are able to adequately meet organizational needs and 15% of the NCCMs have difficulty in maintaining what is an effective control of different situations outside the hospital.

On the more complex needs, which the CCM is able to highlight on several occasions, there are no specific opinions about trying to satisfy them.

These unmet needs have a negative impact on quality of life and the perception of quality of care.

4. Discussion

This work aimed to understand CCM's perception of the needs fulfilled/unsatisfied in caring for cancer patients.

Unmet needs and holistic approach to cancer patients

The literature has shown that the care approach in cancer patients has changed a lot in recent years; in terms of a holistic approach, comprehensive care is Considered a carrier of physical needs and psycho-socio-relational. Often, these needs are challenging to manifest by the patient because they are not detectable by clinical or laboratory parameters (Ried, K. et al. 2021)

Despite scientific and therapeutic advances, in the individual and collective imagination, cancer continues to associate itself with physical and mental suffering, stigma and anguish. Cancer is a traumatic event that alters the individual and interpersonal balance, evoking an atmosphere of uncertainty and involving the entire family system. Scientific research and the experience of clinicians highlight the need to integrate care with holistic care for the person, where the patient and family are consciously involved and participate in therapeutic choices.

The results of the study revealed several unsatisfied or complex needs. The need for a holistic assessment is therefore evident, Deep, that they give voice to people who have more difficulty expressing their needs and worry that these voices are heard (Ayvat, Irem et al. 2023)

Certainly, communication and listening are necessary and fundamental strategies to respond adequately, but the NCCM needs help responding to the person's social needs. The European Commission has published a report on elderly people in the Community (e.g., elderly people alone) and access to land resources. For this reason, the NCCMs are not only responsible for the organisational aspects of care but also for a personalised process that follows the patient.



Other studies have also shown that continuous information provision, support in decision-making, and continuity of care improve the quality of cancer care. It is assumed that a single staff member is needed to manage the cancer care plan and act as a home care manager for patients (Bashkin, O et al., 2023).

The CCM as a reference figure for patient and family

The study's results show that the NCCM is competent to understand the experience of illness and raise concerns during interviews. The European Commission has published a report on the European Union's research and development policy in education. The CCM must promote user openness, the process through which an individual tells himself in the most personal and intimate aspects to another individual.

The NCCM thus becomes a stable reference for patients and creates a relationship of trust with them. Some professionals take care of the patient immediately after diagnosis, but not all follow the patient during all phases of care. This fragmented mode could confuse users and their families, as they may not feel welcomed into a single path but feel "lost." This aspect makes it more difficult to ensure appropriate interventions and monitor the results achieved by analysing expected outcomes.

The respondents emphasize the importance of communication with the patient, particularly in recognizing and accepting their emotions. However, it's noted that there's a wide variety of responses among the interviewees, and not all professionals have equal competence in exercising these communicative skills. The vast majority of professionals interviewed highlighted the moment related to the recognition of patient emotions as a critical aspect of the interview, indicating a potential area for improvement in healthcare communication.

Quality of information and disease awareness

The study shows that the quality of information provided to patients is a key aspect to consider in the course of care because it allows the patient and family to make informed choices and promotes therapeutic adherence.

It is difficult for professionals to know what strategies to implement to meet these needs. Most of the management takes place in terms of longitudinal management: from diagnosis to follow-up, education and global (in all aspects related to care (device, blood tests, therapy) and taking care of the hospital-territory link. In practice, they organize the whole therapeutic diagnostic process.

The CCM, by responding adequately to the needs, doubts, fears and concerns of patients and families, not only improves the quality of care but also validates and understands the patient's situation. This approach promotes the development of disease awareness and the ability of the patient and family to make appropriate choices.

However, although the studies focus much on the communication skills of professionals, even doctors since there is a relationship between sound and open communication also of bad news and awareness/ adaptation of the person to the disease (Butow et al., 2020; Van der Velden et al., 2024) in our study emerges in the very characteristic aspect of the sick



person, its ability to deny the evidence, so that the CCM recognize that, While suffering, anger and anguish, there remains still the desire to continue living.

Limits

Despite the adequate number of interviews, recruitment through sample convenience, and the willingness of the person to be interviewed, he may have selected highly motivated professionals for their work.

Conclusions

The results of the study underscore the significance of a single reference figure for the cancer patient and his family. The figure of the CCM Nurse emerges as this crucial professional, Capable of assessing needs in a holistic way and providing continuous support throughout the care process, thereby reassuring the audience about the patient's ongoing care.

Statements and Declarations

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Ethic Committee: The study was conducted following the Declaration of Helsinki. Participants were informed in detail by the investigator about the purpose of the research and signed specific informed consent to the study and to the processing of personal data, including an informative note clarifying how the research was voluntary participation, with the option to withdraw at any time. Participants could then change or delete the data collected whenever they wished. The information notes also stated that the interview would be audio-recorded and that the data collected and analysed would be disclosed strictly anonymously for research purposes.

Informed Consent Statement: Informed consent was obtained from all subjects involved in the study.

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Conflict of Interest: Each author declares that he or she has no commercial associations (e.g. consultancies, stock ownership, equity interest, patent/licensing arrangement etc.) that might pose a conflict of interest in connection with the submitted article.

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