Care in palliative care: a challenging concept with normative issues

Michael Rechenmacher[1,2]

[1]Clinic and Polyclinic for Internal Medicine III, University Hospital Regensburg, Regensburg, Germany
[2]Center for Palliative Care, University Hospital Regensburg, Regensburg, Germany

Correspondence to
Dr. Michael Rechenmacher; michael.rechenmacher@ukr.de

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ABSTRACT

Palliative care is an approach for seriously ill patients. Illnesses and knowledge of limited life expectancy often limit self-determination among patients. Along with the concepts of patient autonomy and heteronomy, care is central to the everyday personal and institutional lives of the ill. However, the term 'care' has not yet been systematically examined. I argue for a clear distinction between care and paternalism in the discussion about the individual approach to a situation in everyday life, which are two different forms of action in which the patient's will is considered to varying degrees. The (at least ethical) evaluation, and thus the individual situational need for justification of an action, is different for both forms of action, even if both forms can promote the autonomy of the patient. However, not 'all' patient requests are fulfilled through palliative care. There are (justified and perhaps necessary) limitations in the fulfilment of the patient's goals on the part of those providing care. However, in the context of the discussion on care, these limitations also require a well-founded justification for each individual case.

INTRODUCTION

The 'care of those who cannot be cured' is one of the goals of medicine.[1] Palliative care is the discipline of medicine that provides focused and professionalised care for the critically ill and dying by alleviating suffering and distress of a physical, psychosocial and spiritual nature.[2] However, palliative care is not merely end-of-life care. Symptoms that are distressing and require treatment occur not only at the end of life but also in varying intensities over time, from the time of diagnosis throughout the course of an incurable disease.[3]

Saunders, one of the founders of modern palliative care, considered caring as the most important attitude towards serious illness and death. She developed the concept of palliative care as person-centred care that focuses on the patient's needs and understands them as the basis for action on behalf of the sick person.[4] These values are reflected in several national palliative care guidelines. Patient autonomy and care are important elements of patient-centred care.[5]

Autonomy can be understood both as a right (eg, the right to bodily integrity and self-determination) and as a person's capacity or competence to make rational decisions.[6] Respect for autonomy is a key principle in contemporary medical ethics.[7]

Aim of the article

A more systematic analysis of the term 'care' in the context of palliative care has not yet been undertaken, although 'care' is undoubtedly a central aspect and specific challenge in palliative care. This is because care (among other aspects) is expressed in the actions of the healthcare staff and relatives towards and for patients. Each of these actions inevitably affects the autonomy of the person receiving care. The actions can respect, promote, maintain or restore the patient's autonomy; however, they can also restrict or prevent it.

This article aims to outline the concept of 'care'. The aim is to show that the ethically relevant aspects of acts of care can be configured in different ways. A central aspect is whether, or to what extent, the intention of the action corresponds to the will of the patient or family member to receive care, their preferences and values. Two different forms of the action can thus be distinguished in which the will of the care recipient is taken into account to varying degrees. I argue that the actions attributable to care are characterised by the fact that their intention coincides with that of the patient or relative receiving the care. Otherwise, it is a form of paternalism. For this reason, I also advocate a clear distinction between care and paternalism in the evaluation of an individual action because the (at least ethical) evaluation, and thus the individual situational need for the justification of an action, is different for both forms of action.

However, not 'all' patient requests are fulfilled through palliative care. There are certain (justified and necessary) limitations in the fulfilment of the patient's goals on the part of those providing care, not only in situations when the autonomy of the person providing care is affected by the care requested. However, this limitation also requires a well-founded justification for each case.

Autonomy in the context of palliative care

Autonomy is a central concept in palliative care. Acts of care interact with patient autonomy in several ways. In principle, any action perceived as caring can maintain, enable or even enhance a patient's capacity for autonomy. However, it can also have a negative impact. Autonomy can be exercised in two ways: so-called negative freedom generally refers to freedom from external and internal constraints, such as 'freedom from'. This is distinguished from positive freedom, which is defined as 'freedom to'.[8]

Negative freedom essentially comprises the framework within which the medical treatment can occur. First, physicians must determine indications for the treatment based on objective medical parameters. A discussion of shared decision-making between the physician and the patient is held, and informed consent is obtained from the patient. The nature and quality of communication play central roles in this process.[9] The (idealised) concepts of shared decision-making[10] and informed consent[11] are forms in which this respect for autonomy is procedurally framed in everyday medical practice. A patient's decision about medical treatment is usually considered autonomous if three conditions are met. First, the patient makes an intentional and conscious decision. Second, the patient has received and understood all relevant information and is able to process and understand it appropriately. Third, decisions are made without the influence of others, especially coercion, deception or manipulation.[11] For consent or refusal to be considered autonomous, all three conditions must be present, which may not be perfectly but substantially fulfilled.[7] At present, there is no standard definition or consensus on what the term patient autonomy encompasses. The focus on the autonomy concept of a self-determined choice outlined above is often referred to as the 'standard liberal view,' 'mainstream interpretation of autonomy,' or 'default position'. This represents today's dominant understanding (in the Western world) of (patient) autonomy.[12]

In addition to negative autonomy, there are forms of positive autonomy that include actively shaping one's life, identifying with basic values and interacting with the social environment. This approach has special significance in the context of palliative care. Two crucial dimensions for the realisation of positive freedom are (1) ability and (2) the possibilities of the individual to form their preferences and canon of values and to act on the basis of these. Internal factors play a key role here, requiring a minimum of cognitive and voluntary capacity for the individual to decide and act autonomously, and external factors relate to whether the free development and exercise of self-determination are ensured.[8 13] Through the care of all actors (eg, physicians, nurses and health policymakers), palliative care should aim to maintain, strengthen or restore the patient's agency to the extent possible. For the physician–patient relationship, certain aspects, such as the appropriate level of conversations, medical consultation, overcoming institutional barriers and reduction of restrictive rules in the healthcare system, must be regarded.[14]

These aspects of positive freedom in daily care and in the support of seriously ill individuals touch on the autonomy question, including the potential danger of paternalistic action, much more frequently and probably more influentially, than the usually discussed treatment questions of informed consent or therapy limitations.[15] These aspects also play a major role for the affected individuals themselves, as evidenced by empirical data.[16]

Saunders described the total set of limitations of freedom as a component of her concept of total pain.[4] Palliative care attempts to ensure that a sick person, despite the effects of the disease and limitations, can live a life of value and interact with their social environment. Palliative care addresses these limitations through caring actions.[17] Therefore, it is necessary to determine the meaning of the term 'care'.

What is care?

There are different understandings of the term care: a form of labour, a relationship or a type of ethics.[18] According to its broad definition, care embraces all norms, dispositions and actions that aim to promote *the benefit or well-being of other persons*.[7] We use the term care in the sense that we perform certain actions for the benefit of others ('care for' or 'take care of'). Caring actions meet the needs of other individuals.[19] The needs or interests of others are the starting points for these actions.[20] Care, in this sense, is a basic anthropological condition of human existence and thus a basic form of human practice. It is a Christian[21] as well as philosophical concept, exemplified from Kant via Heidegger to Ricoeur,[22] that is, a justifiable duty to help a person in need.

Maio[23] outlined the phenomenology of care in the medical (palliative) context according to which care, under the conditions of strict orientation to the values and preferences of the sick person (patient centredness), is a concrete response to the request of the person seeking help and the individual restriction of their autonomy of action (responsivity) by caring for people or institutions (relationality) in the respective concrete context (contextuality). Care is provided in varied ways in different situations (situativity) and in various forms that are individually tailored to each situation (situational creativity). The caregiver must recognise and accept that there is often no objectively correct solution (tolerance of ambiguity). The complexity of the palliative situation requires careful observation and an accompanying ability to wait (an attitude of allowing things to unfold).

In summary, two broad categories of care in palliative care can be identified in the area of conflict between care and autonomy: (1) actions of a purely 'liberal standard conception', which are initially concerned with free decisions without influence and (2) forms in which the patient is to be deliberated on and/or empowered to make independent decisions or to implement their own goals. In the deliberative model, the physician reflects with the patient on the best course of action in the current situation through a moral discussion that is open to development and revision.[24] Empowerment refers to strategies and measures aimed at increasing the degree of self-determination in the lives of palliative care patients and enabling them to (re) represent their interests in an autonomous, self-responsible and self-determined manner ('helping people to help themselves').[25] Particularly in the second group, the 'active role' of the caregiver increases because they have to play a greater role in the content of the process.[26] This increases the risk of influence and heteronomy. However, care is characterised by the fact that there is (as yet) no influence of an actual (and procedural) nature.

Normativity of care

Chadha-Sridhar[27] argued that care can be constituted by two elements. On the one hand, the word care describes what a concrete caring action entails. Simultaneously, evaluative elements can be identified to assess the quality of an action (eg, good or bad). Thus, care can be seen as a 'thick ethical concept': caring for others in palliative care inevitably has an impact on the recipient of the action and their autonomy.[27] The promotion of negative autonomy is possible by reducing interference from the outside and trying to create the greatest possible equality of opportunity between the sick and the not so sick. Positive autonomy, as the possibility of being the author of one's own life, can be promoted in the context of illness by improving the possibilities of a person with limitations due to illness and enabling them to better shape their life despite these limitations. In doing so, the differences between the two groups are recognised, and an attempt is made through appropriate measures to shape the framework conditions in such a way that they appear to be equally acceptable to all people.[28]

Such care is patient-centred care, as in palliative care. The basis of this interaction is patients' values, preferences and beliefs. They represent the set of values on which concretised care is based.[5 29] Together with the patient's individual framework conditions, they represent a particular individual setting for care characterised by contextuality.[30] This was Saunders' explanation, and her attitude was that she wanted to do everything she could to ensure that the patient not only died in peace but also lived till the end.[4] This patient-centred concept of autonomy is reflected in numerous aspects of everyday palliative care practice: For instance, when in accordance with the patient's preferences, a participatory decision-making approach is used to discuss medical options (such as therapy, symptom control or refusal of treatment) and care options beyond the purely medical (such as everyday life planning). This approach, in addition to professional considerations, generally takes into account the patient's personal preferences and values or attempts to reconcile them. Decisions regarding (palliative) sedation, refusal of (artificial) nutrition and the selection of the place of death are made with respect to the patient's biography and values. In circumstances where a patient's decision-making capacity is compromised, advance planning options, such as living wills or powers of attorney become pertinent. The integration of cultural, religious or spiritual dimensions into end-of-life care can also be considered an expression of a patient-centred approach.

Therefore, it is not merely a question of legitimising care but also of shaping care. From this perspective, I argue that care is normative rather than arbitrary. In any case, the concrete actions of caring actors in the everyday clinical life of palliative care fill the theoretical construct of care with concrete content, making it visible and perceptible. Whether an action by medicine, nursing, or all individuals, professions and institutions involved in palliative care actually constitutes care can be determined through its effect on the promotion of (negative and positive) autonomy.

Relational conception of autonomy in palliative care

Thus, care is characterised by its relationality.[30] In my opinion, in the discussion on how palliative care can promote both negative and positive freedom, autonomy is also presented as a relational conception. However, the term relational autonomy encompasses diverse concepts, each attempting to describe the implications of intersubjective and social dimensions on individual autonomy and moral action.[31] Therefore, it is necessary to determine how the concept of relational autonomy in palliative care can be classified based on previous considerations.

To improve autonomy and provide the best possible care for seriously ill persons in the given conditions, it is necessary to strengthen the social space.[32] The so-called 'weakly substantive approaches' of patient autonomy[13] take into account that affective-emotionally influenced categories (self-esteem, self-confidence and imagination) have a constitutive influence on decisions and understand decisions and actions in the larger context of the patient's personality and their environment. Emotional and, to some extent, physical, in conjunction with the cognitive dimension, results in the coherence of the human personality, which is fragile and susceptible to disruption in many ways, and whose dimensions are in a complex interplay. In my view, this understanding is closer to the practice of life (eg, purely procedural concepts of autonomy, such as informed consent) and closely resonates with that of palliative care.

Finally, in the palliative context, it is important to specify the enabling conditions for autonomy. Thus, autonomy is less understood as a relationally constituted concept. Rather, it appears to be a relational term in the form outlined above: it is an individual ability, which can only be maintained, strengthened or restored in the context of accommodating social conditions and relationships.[32]

Care and dependence

A central consequence of the specific constitution of the palliative situation and a noticeable challenge for the aspect of autonomy is the patient's dependence, which varies from patient to patient; it arises obligatorily from the medical situation on a patient-by-patient basis and is shaped by medical and nursing actions, the necessary individual and institutionally organised support and social conditions. It occurs as a dynamic dimension at different levels and in various forms: physical, mental, temporary, permanent, steady and selective.[33] The question of how to ethically account for dependency in the context of palliative care due to the specific constitution of people and the types of dependency has not been adequately discussed in the literature. Even if caring aims to promote freedom, it will never succeed in completely reducing dependence. Therefore, one goal must be to minimise dependence and not make it more intense than is absolutely necessary.[34]

In reflecting on care, a pertinent question is in what manner do we want to confront human dependencies in our conceptions of autonomy, including autonomy-enabling care, and what value we assign to dependency. This can be considered a limitation or the absence of individual autonomy, which one wants to reduce to the extent possible. However, increasing dependency can also be understood as a constitutive dimension of the meaning of the personal form of human life, as a constitutive aspect of the way in which people lead their lives under certain conditions. Dependency implies a duty that has to be fulfilled individually and collectively in the best possible way and an attitude of solidarity towards the needy.[33]

This duty then concerns not only the conditions for individual self-directed living but also the construction and further development of such social institutions that enable people, even with or despite dependency, to realise their personality and self-determination.[35] This demand applies equally to all persons and institutions that come into contact with seriously ill people, from nursing homes to primary care, hospitals and, last but not least, all components of specialised palliative care.

Paternalism

In the context of medicine and nursing, caring is also understood as care that is exclusively oriented towards the caring ethos of medicine and nursing and that acts for the benefit of the patient, even against the expressed will of the patient, to achieve what is from the perspective of palliative care professionals best for them. However, this does not describe care in the sense outlined above but is considered paternalism. Paternalism is the 'interference with a person's liberty of action justified by reasons referring exclusively to the welfare, good, happiness, needs, interests or values of the person being coerced.'[36] Paternalistic behaviour (heteronomy) is opposed to self-determined actions on the part of the patient (autonomy). Strong paternalism (the correction of values) is distinguished from weak paternalism (vicarious perceptions of interest).[37 38]

Care and paternalism in everyday palliative care

Patient autonomy (in terms of both negative and positive freedom) is often limited in the context of chronic serious illness.[39] Palliative care is about, first, medical or nursing aspects around the treatment of the palliative-defining underlying disease or distressing physical symptoms, such as pain, nausea or shortness of breath.[40] Second, there are restrictions on freedom in an individual's lifestyle due to physical, functional and cognitive limitations, psychological burdens and the constraints and affections caused by them.[41] Third, in the existential threat of a severely limited lifetime prognosis, the accompanying psychological reactions (eg, sadness, fear, worry or guilt) and spiritual questions (regarding the meaning of life, questions about faith and questions about life after death) can severely restrict the seriously ill from the possibilities of freedom.[42] In a palliative care situation, we are often required to deal with the so-called 'hard choices',[43] that is situations in which patients must choose between two options that are suboptimal in each case.

When the patient's part in the intention of an action is diminished (regardless of whether the patient decides for themself or a third party decides for the patient in their best interest while respecting their beliefs and values) and third parties exert influence (to varying degrees and in different ways), the action is paternalistic. Several forms of paternalism have been discussed in terms of ethics. The common characteristic of paternalistic actions (in the medical context) is, therefore, the well-being of the patient but not necessarily or always their full autonomy (therefore, heteronomy).

Paternalistic acts cannot be completely avoided in the context of palliative care: they are factual and, in certain situations, perhaps morally justified. Given the reality of palliative care described above, paternalism is necessary in many situations, at least to an individually varying extent. Therefore, these actions are important. However, paternalistic action is always more or less morally problematic. This is not the case because paternalism is most often realised through coercion in the form of physical or psychological forces or specific incentives.[44 45]

A question arises as to which actions maintain the boundary of capability and non-interference, on the one hand, and (incipient) heteronomy, on the other, and how to ethically evaluate these actions. The transition from appropriate care to paternalism in the everyday practice of palliative care appears more fluid than clearly definable. The boundary between care and paternalism can be understood as a line along which the intention of an action no longer fully corresponds to that of the patient. Depending on the understanding of the term, it lies within the imaginary continuum of deliberation, persuasion and nudging.

Paternalistic actions are not inadmissible if they prevent the patient from endangering themselves, even against their actual will.[7] They may promote or restore autonomy. In complex palliative care situations, certain forms of paternalism do not necessarily appear to conflict with autonomous decision-making. A significant proportion of palliative care patients want their physicians to decide the best course of action.[46]

Some scholars have argued that nudging, also called libertarian paternalism, is a form of manipulation. Nudges are small, systematic changes or impulses in a person's decision-making process that have a certain probability of influencing the person's subsequent actions. Nudging is thus ethically classified as persuasion, which is still mostly considered ethically justifiable, and as a form of soft paternalism, which is judged inconsistently with respect to ethical justifiability.[47] Information on the meaning and ethical classification of nudging in the context of palliative care is limited. In the interaction between physicians and patients, the possibility of nudging inevitably arises. This can occur consciously, but in everyday clinical practice, probably even more often unconsciously, although in my opinion, it often plays a role in everyday palliative care. The libertarian paternalist approach and shared decision-making paradigm are not mutually exclusive.[48]

Paternalistic actions are not inadmissible if they prevent the patient from endangering themselves, even against their actual will.[7] They may promote or restore autonomy. In complex palliative care situations, certain forms of paternalism do not necessarily appear to conflict with autonomous decision-making. A significant proportion of palliative care patients want their physicians to decide the best course of action.[46] Some scholars have argued that nudging, also called libertarian paternalism, is a form of manipulation.

Ultimately, I believe that a clear and conscious distinction should be made between care and paternalism in the use of these terms in everyday life. Two different forms of action are described, whose (at least) ethical evaluations may differ, although they may both promote autonomy because the proportion of the patient's will in these actions is different.

Ethical assessment of a caring act

Finally, the question of whether a caring act in palliative care is justified cannot be answered on the basis of general moral principles or the distinction between care and paternalism. Rather, an ethical assessment of an action can only be made based on its morally relevant characteristics.

First, it is necessary to ascertain whether—and to what extent—the action under consideration is not only a medical or nursing matter, but also a moral issue, as is often the case in everyday palliative care. For example, administering morphine with the aim of alleviating pain is not only of pharmacological relevance, but also of ethical significance, as it serves to reduce suffering. The professional question of whether the individually selected dose of morphine is sufficient to alleviate physical symptoms also has a normative aspect when it comes to whether it is ethically justifiable to administer a (medically 'correct') dose if it may nevertheless shorten life. A nurse who allocates sufficient time to the washing of a bedridden patient is not merely adhering to good hygiene practices; she is also demonstrating respect for the individual's state of vulnerability, thereby engaging in a profoundly normative gesture. When initiating antibiotic therapy, the professional dimension is whether the drug has a good chance of success in treating the specific infection, and at the same time, the normative component is whether it is appropriate to prolong life in view of the patient's subjective suffering if the treatment only prolongs life minimally. When determining the presumed will of the patient, the technical question is how this can be appropriately reconstructed; the normative question addresses whether it would be right to refrain from life-prolonging measures despite continuing uncertainties with regard to the exact wishes. In palliative care in the patient's home environment, a technical question addresses how relatives can safely administer strong painkillers in a pain crisis; this situation also involves normative issues as to whether it is justifiable for relatives to be given this responsibility.

For the evaluation of a concrete caring action in everyday practice, a set of different questions could be helpful in the individual evaluation process to (1) distinguish between care and paternalism and (2) evaluate the action with regard to its ethical criteria and thus clarify whether a certain action (regardless of whether care and paternalism) is required and can be reasonably justified in a certain situation.

The conceivable aspects here are as follows:

- *Actual will:* is the will known? Is the expressed will the actual will? Factors, such as rationality and authenticity, also play a role.[49] (These aspects are based on a coherentist model of personal autonomy: autonomous choices are generally not determined by individual values alone but by a complete network of coordinated, coherent desires and attitudes.) In the palliative context, questions about diachrony and narrative identity[50] may also be important. (These are questions about whether and to what extent a person's past is relevant to a current, authentic decision.) Alternatively, if the will is judged to be deficient, then the extent and nature of the deficit must be determined. Is the will known but not

considered authentic? Is the patient incapable of making a decision?
- *Intention of the action*: what is the good to be realised? Is it the patient's autonomy, a value, a norm or the actor's own ideas?
- *Means* used to act in a caring way: none, liberal attitude, tolerance, persuasion, nudging, incentives, coercion and other means of paternalism.
- Quality of the physician–patient relationship (comparable relationships with other professional groups): what role does trust play in this vulnerable group of patients?
- Any other aspects that are appropriate for the ethical evaluation of an individual's situation.

Care is linked to numerous established ethical frameworks in medical ethics or can be understood as part of some of them. When evaluating or justifying an action, these frameworks can be taken into account: In Principlism,[7] on the one hand, with the principle of respect for autonomy (someone no longer wants to eat: care requires respecting the wish, but at the same time empathically questioning whether it is a free decision or an expression of hopelessness that needs to be addressed in other ways of care); also in the sense of care as a lived principle of benevolence (when a nurse takes time to talk to a dying person despite time pressure, not because it is 'medically necessary', but rather because it is 'humanly necessary'). A connection can also be drawn in the context of care ethics,[20] which prioritises responsibility, relationships and concreteness over abstract rules (a doctor decides not to take any further invasive measures despite the medical possibilities available because they know the patient and know what is important to them; because the relationship, and not just a medical algorithm, guides their actions). In deontological ethics, an action can be evaluated according to the principle of care (instead of directly complying with a request for euthanasia, the doctor, mindful of the moral duty of care, offers alternative palliative measures such as more intensive pain therapy or discussions about fear). In teleological ethical approaches, which evaluate the outcome of an action, there are also points of reference for care (decisions motivated by care are aimed at enabling the patient to live a life that is as free from suffering as possible in accordance with their values, even if this means foregoing life-prolonging measures).

The second aspect, that is, the ethical evaluation of an action, expands the view of the aspects relevant to the evaluation of whether an aspect or a patient's request fits into the category of care from a moral point of view. In addition to the patient's values, the values of other persons affected by the action (especially relatives) also count, with different weightings that need to be discussed. In particular, patients' values affect those of the persons providing care (such as physicians and nurses). The extent to which these should be determined is a matter of discussion. At least in ethically challenging situations (eg, physician-assisted suicide), they must find their appropriate place. As valuable as these aspects may be in theory for our actual question - the distinction between care and paternalism and the ethical evaluation of an act of care - they also often harbour the danger of paternalism or cannot always be clearly determined in everyday practice.

Starting point for further considerations

This article has clarified one research question. Simultaneously, it has raised several additional questions that require further research. It would also be worth investigating in more detail which catalogue of aspects could be helpful in the ethical assessment of a caring action and whether and how the criteria could be weighted, at least in the event of a conflict. In addition, a differentiated comparison of different concepts of (patient) autonomy in the context of the ethical evaluation of different actions would be a good addition. Finally, examining the perspectives of physicians and patients would be a crucial research goal. The present article focused on medical and nursing aspects. An important enrichment would be the inclusion of the views of other professionals involved in palliative care on the relevant dimensions of the concept of care.

Conclusion

Care is central to palliative care, not merely because it is a part of the name. Rather, care is the central motivation for many actions and approaches in palliative care. Although both categories of action, that is, care and paternalism, aim to promote well-being, they highly differ in their legitimacy, respect for the patient's goals and values, and ethical evaluation such that they should be clearly labelled as two different categories. The above considerations provide each actor with a set of aspects for everyday life on the basis of which they can categorise their specific action into care and paternalism and justify it in a specific situation. This justification can also lead to the fact that a certain action has not yet been performed. Structuring the relevant arguments of the individual caring action not only helps the caregiver to justify it personally but also provides a basis for further discussions, such as with the patient, relatives or in supporting palliative care teams.

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