Review Article

Patients' Autonomy at the End of Life: A Critical Review

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Abstract

Context. The predominating definition of autonomy as a capacity to make an independent rational choice may not be suitable for patients in palliative care. Therefrom arises the actual need for more contextualized perspectives on autonomy to promote the quality of life and satisfaction with care of terminally ill patients.

Objectives. This review aimed to develop a theoretical structural model of autonomy at the end of life based on patients' end-of-life care preferences.

Methods. In this review, we used systematic strategy to integrate and synthesize findings from both qualitative and quantitative studies investigating patients' view on what is important at the end of life and which factors are related to autonomy. A systematic search of EMBASE (OVID), MEDLINE (OVID), Academic Search Complete (EBSCO), CINAHL (EBSCO), and PsycINFO (EBSCO) was conducted for studies published between 1990 and December 2015 providing primary data from patients with advanced disease.

Results. Of the 5540 articles surveyed, 19 qualitative and eight quantitative studies met the inclusion criteria. We identified two core structural domains of autonomy: 1) being normal and 2) taking charge. By analyzing these domains, we described eight and 13 elements, respectively, which map the conceptual structure of autonomy within this population of patients.

Conclusion. The review shows that maintaining autonomy at the end of life is not only a concern of making choices and decisions about treatment and care but that emphasis should be also put on supporting the patients' engagement in daily activities, in contributing to others, and in active preparation for dying. J Pain Symptom Manage 2019;57:835–845. © *2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Autonomy, palliative care, end of life, terminally ill, quality of life, patient preference

Introduction

There exists no universal definition of patients' autonomy, and there is no consensus about what it means. At the same time, the dominant emphasis on individual autonomy defined as a capacity to make an independent rational choice, which has a significant influence on principles biomedical ethics,[1] is being criticized for failing to inform nursing and care for seriously ill and older patients.[2] In modern medicine, the liberal emphasis on individual freedom and resistance to a controlling authority[3] is represented in legal disputes articulating patients' rights to receive care consistent with their preferences.[4]

The critics of the mainstream bioethical approach argue that, on the one hand, the principle of autonomy does not distinguish between "respecting autonomy" and "promoting autonomy"[5] and, on the other hand, that this limited understanding of autonomy as the capacity to make individual choices ignores the important role that autonomy plays in the constant process of adaptation to opportunities and limitations in the interaction with the world.[6]

There is growing evidence reflecting the general priorities and preferences of people in advanced stages of life-threatening illnesses.[7–9] The diversity of the results supports the suggestion that end-of-life

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needs are multidimensional[10] and strictly individual. Interview- or questionnaire-based research usually generates a list of items that are considered important by most participants. The list encompasses different domains of experience (physical, psychological, social, and spiritual), which gives an image of how the advanced disease impacts the functioning and understanding of everyday life. There is a strong agreement that the key for improvement of end-of-life care is to make the care consistent with patient preferences by an individualized process of decision making.[11]

The legal concept of informed consent and advanced directives grounded in the ethical principle of individual autonomy has been implemented to reach this goal. But some studies show that this decision-making approach does not match the needs of many patients and their families.[12,13] Therefrom arises the actual need for more contextualized perspectives on autonomy that would be more suitable for the situation of patients at the end of life and would help to promote the quality of their life and satisfaction with received care.

Mars[6] identifies different conceptualizations of autonomy in the context of chronic physical illness. First of them is defined by Dworkin.[14] For Dworkin, autonomy constitutes a critical rational reflection of desires. However, the advocates of relational autonomy[15] argue that such reflection is not necessarily rational but may involve emotions, imagination, and creativity. They stress the importance of relationship and social interdependence, only through which autonomy can be shaped. Agich[16] argues that patients' capacity for reflection of their desires can be jeopardized by chronic illness, and he proposes a model of actual autonomy, which is built upon everyday activities by accommodation and adaptation to the new circumstances in structures of meaning. He also describes how the perception of autonomy simply as of individual freedom and self-determination can cause conflicts in the context of the patients' dependence on others, which can be manifested as the denial of need, hostility to the carers, and the feelings of guilt for being a burden.[16]

Hedgecoe's critique[17] of the classic bioethics model of autonomy points out significant differences between theoretical bioethical analyses and the ethical reasoning that takes place in real clinical situations. He suggests using empirical social science in bioethics to get the bioethical discussion more empirically rooted.

Aim

This review aims to develop an evidence-based, structural model of autonomy of patients at the end of life by analyzing end-of-life care preferences related to autonomy, as expressed by the patients themselves in available literature.

Method

A systematic review strategy was used to integrate and synthesize the findings from both qualitative and quantitative studies. This design was chosen to gain broader knowledge by including studies investigating patients' preferences from both methodological perspectives. Combination of quantitative and qualitative data is recommended when the aim is to build a theoretical model, rather than to generalize knowledge by comparing the results of particular reviewed studies,[18] which applies to our study. As this is a review study, ethics approvals were not required.

The interpretation of the results was based on the concept of autonomy as developed by Agich,[16] stressing the importance of interdependent and social factors in understanding and promoting the autonomy of frail people. To develop a theoretical model of autonomy of people at the end of life, we decided to analyze the studies of the patients' preferences, and to identify which of those preferences are connected with autonomy understood as a meaningful adaptation to the new circumstances and situations at the end of life.

In the analysis, the demands of the integrative review method were met.[19] Open and axial coding techniques and constant comparison method[19] were used to achieve synthesis by subsuming the concepts identified in the primary studies into a higher-order theoretical structure.

Eligibility Criteria

In this review, based on the Agich model explained previously, we understand autonomy as a concept expressed by patients' preferences so the search was designed to gather studies on patients' preferences. The term autonomy itself was intentionally not included in the search strategy. Qualitative and quantitative studies were included if they provided primary data from patients with advanced stage of chronic diseases and were published between 1990 and 2015 in English, French, and Czech peer-reviewed journals. Papers that did not provide primary data from the patients—reviews, editorials, letters, primary data from health professionals—were excluded, although they were used for double-checking references to identify studies potentially missed by the initial search.

Studies providing primary data gained from family members were not included because the main goal of this study was to derive definitions of autonomy exclusively from the patients' perspective. Studies focusing on one specific preselected aspect of

Table 1
Search Strategy

1. preferences, priorities, values, attitude to death - combined with OR
2. patients, family, caregiver - combined with OR
3. terminal care, palliative care, end of life - combined with OR
4. English, French, Czech - combined with OR
5. 1 AND 2 AND 3 AND 4

patients' priorities, for example, treatment priorities or place of death preferences were also excluded, as well as papers about advance directives or advance care planning that did not provide further specific information about patients' priorities.

Search

Key terms used in search strategy are summarized in Table 1. The following databases were used: EMBASE (OVID), MEDLINE (OVID), Academic Search Complete (EBSCO), CINAHL (EBSCO), PsycINFO (EBSCO). We identified 5524 articles through database searching and 16 studies through other sources. After removing duplicates, abstracts screening, and assessment for eligibility (Fig. 1), we finally included 19 qualitative and eight quantitative studies (two of them[20,21] reporting on one study) in the review (Table 2) providing data from 2924 patients with advanced chronic disease. Reference lists of identified studies were manually searched to identify other potentially relevant articles.

Findings

Two core structural domains of autonomy as viewed from the perspective of patients at the end of life were identified—"being normal" and "taking charge." Both domains could be thematically summarized as "active participation in normal life while dying." Each of the two domains is further analyzed from two perspectives that emerged from the analysis: perceptional perspective and activity perspective (Fig. 2). The perspective of perception builds upon the preferences that describe the patients' feelings and perceptions that allow them to feel autonomous in the way as a meaningful adaptation to their situation. The perspective of activity is focused on the preferences that allow patients to actively shape their life at its end (e.g., to manage their time, help others, fulfill their needs).

Based on Agich's model of the autonomy of everyday experience that derives from both affective and rational ways of relating to the world, these two domains take into account the circumstances and clinical realities of people with advanced disease. That reveals specific aspects of the autonomy of people in this

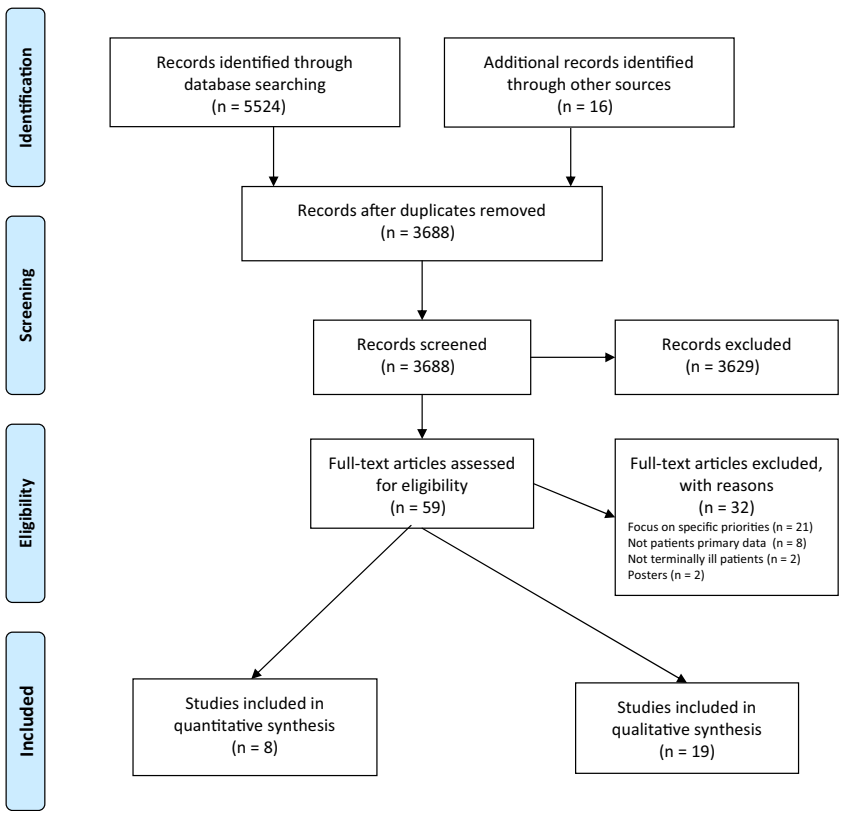

Fig. 1. PRISMA flow diagram.

Table 2
Summary of Included Studies

Author	Year	Methods	Participants	No. of Patients	Age	Gender	Thematic Outcomes
Carter	2004	Qualitative	10 cancer patients	10	80% above 50	70% female	Personal factors (participation in daily activities, lack of energy), interpersonal responses, future issues (loss of meaning of plans, reconsider life priorities), perception of normality, taking charge (ability to define and actualize needs, process of adaptation, accepting assistance from others)
Aspinal	2005	Qualitative	10 palliative care patients, 65 caregivers	10	Above 18		Seven themes identified as most important: symptom management, choice and control, dignity, quality of life, preparation, relationship, continuity. Patients prioritized issues around preparation, relatives and professionals empathized symptom management, relationship, and quality of life.
Steinhauser	2000	Qualitative	14 patients, 61 caregivers	14	26–77, mean age 48	60% female	Six thematic outcomes: pain and symptom management, clear decision making, preparation for death, completion, contributing to others, affirmation of the whole person
Vig	2003	Qualitative	Advanced heart disease or cancer patients	26	52–86, mean 71	100% male	Three thematic outcomes: living while dying, anticipating a transition to active dying, receiving good health care. Rating importance: 1, being able to do things for myself; 2, spending time with family and friends; 3, control of pain
Volker	2004	Qualitative	Seven advanced cancer patients	7	46–76, mean 59	85% female	Six thematic outcomes: protection of dignity, control of pain and other symptoms—pain under control, management of treatment, management of how remaining time is spent, management of impact on family, control over the dying process
Piamjariyakul	2014	Qualitative	30 ethnic minority patients with advanced cardiovascular illness	30	13 p. below 70 y., 17 beyond 70 y.	66% female	Five thematic outcomes: importance of family involvement in care, being pain free, having a comfortable environment for death, wanting no procedures for prolonging life, desiring a relationship with a professional for end-of-life decision making
MacPherson	2012	Qualitative	10 COPD patients	10	58–86	90% male	Five thematic outcomes: information provision, discussion about the future, decision making, planning for future, place of care
Clayton	2005	Qualitative	19 advanced cancer patients, 24 caregivers	19	36–83, median 68	74% female	Four thematic outcomes: treatment decision at the end of life, discussing future symptoms, preferences for place of death, discussing the terminal phase
Goodman	2013	Qualitative	18 patients with dementia	18	68–92, median 84.7	72% female	Three thematic outcomes: "dementia and decision making"—having dementia combined with living in nursing home makes them accepted that decisions are made by others, "everyday relationships," "place and purpose"—loses have impact on their purpose of life
Horne	2012	Qualitative	25 lung cancer patients, 19 caregivers	25	47–85	72% male	Four thematic outcomes: facing death when it comes (focus on living in the present, "carry on as normal"), planning for death not dying, disclosure of the prognosis, clinical discussion about future.
McIlfatrick	2006	Qualitative	Eight palliative care patients, 16 caregivers	8	50–88, mean 74	62% female	Four thematic outcomes: to define palliative care, coordination, communication, and continuity of care. Social support, community care, and long-term planning.
Thomas	2009	Qualitative	Two advanced cancer patients	2	67	50% female	Four thematic outcomes: accept the theme of dying, desire to engage in normal activities, independent decision making, choice of place of death
Payne	1996	Qualitative	18 advanced cancer patients, 20 caregivers	18	30–81, mean 65	50% female	Thematic outcomes: descriptions of a "good death"—dying in one's sleep, dying quietly, with dignity, being pain free, and dying suddenly.
Gardner	2009	Qualitative	10 elders with advanced lung or cardiac disease, 10 caregivers	10	64–100, mean 85	50% female	Four thematic outcomes: challenges (to experience physical and functional decline, participate in normal daily activities, accepting dependence, difficulties to cope with uncertain future), worries (pain and suffering, becoming a burden), concerns about end-of-life care (consistent and responsive care, being treated with dignity and respect, as whole person), living with dying (focus on living, having a measure of control in their lives, and choice in the care)

Singer	1999	Qualitative	126 patients (48 CKD, 40 HIV, 38 residents of long-term care facility)	126	20->85, mean 55	62% male	Five thematic outcomes: receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control over end-of-life decision, relieving burden (three domains—physical care, witnessing death, substitute decision making), strengthening relationships with loved ones.
Pierson	2002	Qualitative	35 AIDS patients	35	Mean 41	91% male	11 thematic outcomes: symptom management, quality of life (without suffering, not having a prolonged life), having loved ones around, dying process (while sleeping, being awake, fear of violent death), place of death, sense of resolution (dying without unresolved issues, say goodbye, time to prepare), control over treatment (being involved in decision, to cease treatment if they want), spirituality, physician-assisted suicide (to escape unbearable pain), medical care (good access, good relationship, whole person approach), acceptance of death (by patients and by loved ones)
Goldsteen	2006	Qualitative	13 terminally ill patients, 26 caregivers	13	39–83, mean 64	77% male	Five thematic outcomes: awareness and acceptance, open communication, living life till the end (normal life, deal actively with the situation), taking care of final responsibilities (funeral, bereavement), dealing adequately with emotions
Ek	2008	Qualitative	Eight advanced COPD patients	8	48–79	63% female	Five thematic outcomes: common structure (limited living space, changed lifestyle, challenged self-image), lacking physical strength, forgoing normal activities (increasing dependence, influence on family), being socially and existentially alone, experiencing meaninglessness
Romo	2014	Qualitative	20 palliative care patients	20	67–97	65% male	Two thematic outcomes: maintaining a sense of control (sense of control without being in control, focusing on living, being comfortable), decision making in the context of ambiguity(uncertain future, contextuality of decisions)
Miccinesi	2012	Quantitative	88 advanced cancer patients	88	Mean 66.3	63% female	Thematic outcomes: 77% declared to be willing to talk about what it is important at the end of life in case of worsening of their conditions, 31% prefer to be left alone in difficult moments, 67% choose home as the preferred place of death, 63% think it is preferable to die in a state of unconsciousness induced by drugs 40% consider very important to find any meaning at the end of life, 50% responders declare to believe in any kind of life after death.
Rocker	2008	Quantitative	118 advanced COPD patients	118	Mean 73.3	53% female	Thematic outcomes: not being kept alive on life support when there is little hope for meaningful recovery (54.9% of respondents), symptom relief (46.6%), provision of care and health services after discharge (40.0%), trust and confidence in physicians (39.7%), not being a burden on caregivers (39.6%).
Heyland	2005	Quantitative	440 advanced disease patients, 160 caregivers	440	Mean 71.2	51% male	Thematic outcomes: 56% to have trust and confidence in doctors, not to be kept alive on life support, 44% to complete things and prepare for life's end, information about disease communicated in honest manner, 42% to adequate plan of care, not to be physical or emotional burden to family, 39% to have relief of symptoms.
Steinhauser	2000	Quantitative	340 seriously ill patients, 1022 caregivers	340	Mean 68	78% male	Thematic outcomes: 26 items were consistently rated as being important (>70% responding that item is important) across all groups, including pain and symptom management, preparation for death, achieving a sense of completion, decisions about treatment preferences, being treated as a 'whole person. Eight items received strong importance ratings from patients but less from carers, including being mentally aware, having funeral arrangements planned, not being a burden, helping others, and coming to peace with God.
Heyland	2010	Quantitative	361 patients with advanced disease, 193 caregivers	361	Mean 76.6	52% male	Thematic outcomes: high-priority areas from the perspective of patients—sense of dignity, good care in absence of informal carer, health care workers work as a team, compassionate and supportive doctors and nurses.

(*Continued*)

Table 2
Continued

Author	Year	Methods	Participants	No. of Patients	Age	Gender	Thematic Outcomes
Downey	2009	Quantitative	352 advanced disease patients, 318 nonpatients	352	Mean 69.3	53% female	Thematic outcomes: top five priorities for at least 25% of respondents—spending time with family and friends, pain control, breathing comfort, maintaining dignity and self-respect, being at peace with dying, human touch, avoiding strain on loved ones, avoiding life support.
Heyland	2006	Quantitative	440 advanced disease patients, 160 caregivers	440			Thematic outcomes: 56% to have trust and confidence in doctors, not to be kept alive on life support, 44% to complete things and prepare for life's end, information about disease communicated in honest manner, 42% to adequate plan of care, not to be physical or emotional burden to family, 39% to have relief of symptoms.
Reinke	2013	Quantitative	376 COPD patients	376	Mean 69.4	97% male	Thematic outcomes: symptom control, preparation for death (financial part, avoid strain the family, feeling at peace, say goodbye), spending time with family and friends, personal concerns (maintaining dignity and self-respect, being touched).

situation and allows us to understand their needs better.

Being Normal. First major domain of our structural model of patients' autonomy in a state of advanced illness is "being normal."

From the perceptional perspective, this domain consists of the perception of the normality of the body in contrast with the changes of the body[22,23] emerging due to physical symptoms (pain, dyspnea, weight loss) and the progression of the disease. Good management of current symptoms as well as of the future development or the dying itself was mentioned in most studies as one of the most important concerns. The need for human touch[24,25] is pointed out in some studies as something important that is lost and missed due to progression of the disease. Human touch was interestingly valued as more important by COPD patients than by other hospice patients.[24] Another important aspect of this domain is physical strength—the perception of having enough energy or strength to do everyday activities, or, on the contrary, experiencing the lack of energy[22,23,25] plays an important role in the perception of dependence.

From the activity perspective, following aspects of patients' preferences are strongly connected with their understanding of being autonomous: there is a strong wish or yearning to continue in normal daily activities,[23,26–28] pronounced as "living while dying",[29] "to carry on as normal" or "to strive in roles",[30] and "to focus on living".[27,31,32] While for some patients it means to live in the present and not to think about the future,[22,30,32] for other patients an important part of being normal, which "gives sense of meaning",[29] seems to consist in making plans for the future, making daily plans,[29] making plans for the remaining time[33] or even making unrealistic plans.[34] Other activity, which seems to be important to the patients and which is often dispraised by carers in the circumstances of dependence and disability, is helping others or contributing to others, either family members or other patients or staff, by passing on knowledge and experiences, giving gifts, spending time together.[33, 35–36]

Taking Charge. The need for active control over one's own life is pronounced in the second domain of this model of patients' autonomy, which we call "taking charge." We argue that this active control taken by patients must not be understood only as their capacity to make a rational independent choice, mainly in the situation of advanced disease and dependence on others, and that the results of the studies on patients' end-of-life care preferences show more differentiated view on this issue. Here again, we identified those preferences in which their fulfillment does not lead only

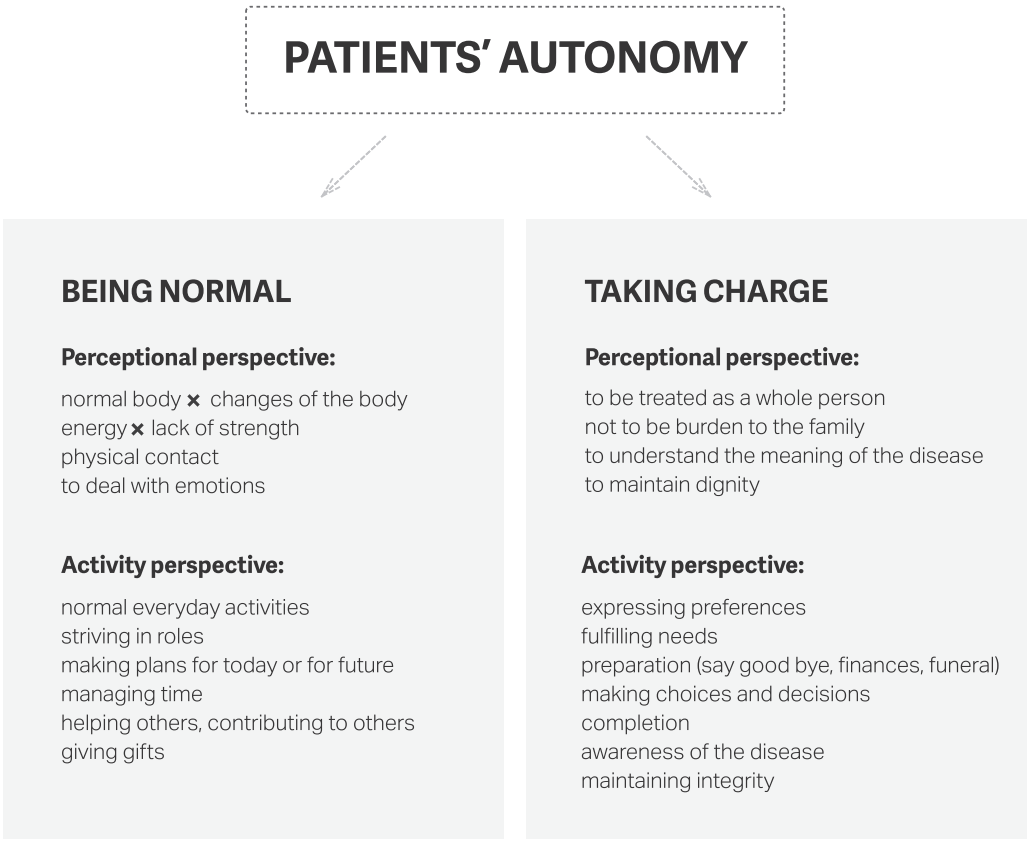

Fig. 2. Structural model of autonomy for patients at the end of life.

to better quality of life, but which can also contribute to better understanding of patients' autonomy. Based on the findings of this study, we propose that this domain can also be comprehended from two perspectives.

The perception perspective of this domain describes the prerequisites for active participation or obstacles that hinder it. Being treated as a whole person is mentioned in some studies,[24,32,34,35,37] mostly related to the relationship with health care providers, but by further exploration, it is always connected with preserving or protecting one's dignity,[24,25,27,33,38,39] being treated with respect and with mutual trust,[29] and being treated as an individual[40] by others in general. If we put those preferences in relation to autonomy then its interindividual characteristics become more evident. Another important aspect in this domain is the patients' feeling of being a burden to their family[24,34,39,41] or society. This can either compromise the patient's autonomy and lead to the erosion of their self-confidence, of their will to act, of their will to discuss difficult topics,[30] or of their willingness to choose a surrogate decision-maker[42] so as not to frighten the family. Or, on the contrary, it can support the patient's autonomy by strengthening the effort to diminish this negative impact on the family, for example, by preparing an adequate plan of care[21,24] or preparing the others for one's death.[29,33]

Activity perspective of "taking charge" provides a picture of autonomy, which is close to the traditional understanding of this term in bioethics. But further analysis of patients' preferences shows that we can expand the range of strategies by which patients pursue their goal of having the preparation for the end of life under control beyond the dogma of independent decision making. Rather, it is defined in many different ways. In Carter's study,[22] where "taking charge" was identified as a central theme, active engagement in the control over the dying process was expressed by participants as "adoption to a range of coping strategies." In other studies,[33,40] the control over the dying process was understood more in the sense of control over decision-making concerning treatment,[32,33,36,37,43] care, and social interactions.[40,42] Romo[31] identifies four different strategies patients use to express their preferences and make their choices: 1) direct articulation of what they want, 2) third-party analogy—expressing the preference by rejecting someone else's decision, 3) adaptive denial—accepting that the disease will progress, but "putting further thoughts in background," 4) engaged avoidance—actively avoiding to think of the end of life and one's choices.

The preparation for the period near death constitutes the second factor of taking charge. Many studies

argue that to be prepared is part of good dying.[27,29,34,35] The preparation for dying and death itself is often connected with the awareness of the disease or the need for being provided with information. There are many reasons why patients want to know what to expect from the process of dying,[35] why they want to be able to anticipate the transition to active dying,[29] and to discuss the future.[27,34] Among the most important motivations, there is a desire to minimize the burden for their family after their death, to have the financial and relational affairs settled,[27,29,33] and to prepare the relatives for the burial and bereavement.[28] Based on our analysis, we argue that this is a fundamental aspect of personal autonomy, which does not figure in the traditional concept of autonomy.

Broader motivation for the preparation for the last stage of life is connected with spirituality and the search for meaning at the end of life. Resolving conflicts, reviewing one's life, saying good-bye to relatives, and being in peace with God[20,37–39,44] can apparently provide this sense of meaning[22] for some patients at the end of life.

Discussion

In this review, we have developed a structural model of autonomy from the perspective of seriously ill people. We summarized the results relevant to the phenomenon of autonomy from the studies on patients' end-of-life care preferences and divided them into two thematic groups. By analyzing the thematic outcomes of the studies from the perceptional point of view, on the one hand, and from the activity point of view, on the other hand, we identified several important aspects of the patients' understanding of autonomy, mainly in the activity point of view, which can help to better understand the complexity of this concept.

The model of autonomy at the end of life built upon the patients' care preferences shows autonomy as a meaningful comprehension of patients' physical, emotional, and social situation and the role they play in this situation. An important review on the evolution of the understanding of the concept of self-determination (taken as a synonym to autonomy) in palliative care was published by Bakitas,[45] where some attributes of self-determination described are similar to the ones in our model: for example, possessing physical and emotional strength, the need of information, and the desire for control. Bakitas further highlighted the concept of self-determination as a manner of protection of patients from coercion and violation of their rights, which is relevant for involving palliative care patients in the research.

Recent literature reviews on patients' end-of-life preferences can also present a valuable contribution to our discussion. These surveys analyze similar data but with the intention to summarize patients' preferences, not with special focus on the concept of autonomy. Virdun et al.[7] analyzed in their systematic review eight quantitative studies reporting on 3117 family members and 1141 patients dying in hospital settings and identified four domains considered important for them: effective communication and shared decision making; expert care; respectful and compassionate care; and trust and confidence in clinicians. By further exploration of those domains, we can see that most of them are concerned with how the patients should be treated to relieve their suffering, and contrary to our findings, there is only a narrow part concerned with the patients' active engagement, mostly in the domain of effective communication (to prepare for the end of life) and shared decision making (making choices about the treatment, nominating a surrogate decision-maker). The explanation for that could be that the studies in Virdun's review were exclusively from hospital settings.

In Meier's review[8] of 36 mostly qualitative studies on the definition of good death from the perspective of different stakeholders, there is a broader list of items (11 themes and 34 subthemes) considered important at the end of life. The active engagement of patients, which is an important aspect of our model, was often pronounced as accepting death and saying good-bye as a part of life completion, having a sense of control over treatment choices, and maintaining independence. Living as usual, maintaining hope, pleasure, and gratitude, and physical touch were also mentioned in some studies.

Rodriguez-Prat et al. in the systematic review[46] about the relationship between autonomy and dignity at the end of life described dignity as a part of the patients' identity and the decrease of their dignity at the end of life due to the loss of functionality. Some aspects of dignity in this study are similar to the aspects found in perceptional perspectives in our autonomy model. But the description of autonomy as a determining factor of perceived dignity in the Rodriguez-Prat review is limited to the traditional understanding as the desire for having control over the dying process and the desire for self-determination. Dignity and autonomy may overlap in some aspects, but they still represent two distinctive concepts, which have their specific complexity.[47]

Upon our findings, it seems that maintaining autonomy is not only a concern of making choices and decisions about the treatment and care but that emphasis should be also placed on supporting the

patients in their daily activities, contribution to others, and active preparation for dying.

Our analysis was inspired by the ethical framework for long-term care proposed by Agich.[16] He argues that to acknowledge autonomy, it is important to treat a person as an individual with personal experiences, history, and needs but also to support his active engagement in their fulfillment. Applying this model in the setting of end-of-life care allowed us to focus on the patients' activity in a broader context and also to delineate the differences from long-term care, such as the emphasis on the active preparation for dying or on the awareness of the disease.

We believe that the aspects of autonomy presented in our findings are often mentioned by patients, but their significance is not recognized or understood as related to autonomy by carers and researchers for two reasons. First, there is a strong general opinion that autonomy means independent and rational decision-making, and second, the seriously ill patients can be seen as more or less passive recipients of care, and the social interaction and the mutual contribution of patients and carers to each other is undervalued. To acknowledge and to support these aspects of autonomy, the conception of autonomy based on everyday experience and everyday activities and interactions can encourage the patients to be as active as possible; it can relieve their stress and minimize the fear of being a burden. This fear, often mentioned by seriously ill patients,[7,27,36] is not only a source of stress, but it can also be a motivation for requesting assisted suicide or euthanasia.[48–50] We believe that the understanding of autonomy presented in this study can be a plausible contribution to this discussion, in which autonomy understood as simple self-determination usually serves as pro-euthanasia argument.

This review has several limitations. First, the search was restricted to peer-reviewed articles written only in English, French, and Czech. Second, studies providing data from bereaved family members and health care professionals were excluded, although they can inform the debate about patients' autonomy, especially in the final days of the patients' lives, when it is difficult to get direct information from the patients themselves. Third, the quality of selected studies was not evaluated by a specific tool, such as Effective Public Health Practice Project Quality Assessment Tool or Cochrane Collaboration Risk of Bias Tool. Fourth, although all studies included in the review were focused on patients' preferences at the end of life, their specific objectives (preferences, good death, quality of life) and also their populations were different (advanced cancer, COPD, neurological disease).

Conclusions

Supporting the autonomy of patients is considered an important principle of care at the end of life, and the results of this review highlight that autonomy should not be reduced to the simple process of decision-making. Future research should address the presented conceptual model of autonomy from the perspective of family members and professional caregivers to apprehend how they understand the autonomy of their seriously ill relatives or patients and to investigate more deeply the interconnectedness of those perspectives.

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