Autonomy and Dependency in an Ethic of Care for the Frail Elderly

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This article synthesizes contemporary research on ethics in long-term care of the frail elderly population in order to propose a framework with which to critique current long-term care practices. Polivka focuses on balancing the elders’ need for autonomy with their increasing dependency. He maintains that services currently available have been driven by cost containment and cost effectiveness. Challenging this prevailing, rigid paradigm, Polivka calls for a more flexible one that responds to the individual needs of aging people.

KEY WORDS: ethics; long term care; aging; autonomy; dependency.

We have not paid sufficient attention to the ethical dimension of the debate over health care policy for the elderly, especially the frail elderly with chronic conditions and impairments requiring long-term care. We have been absorbed with cost-containment, efficiency, and cost-effectiveness issues and have tended to pay little attention to the many ethical and moral assumptions inherently related to these issues which are most commonly treated as technical matters. I think this is a manifestation of what Charles Taylor (1991) describes as the domination of instrumental reason in the conduct of contemporary policy studies. According to Taylor:

Instrumental reason has also grown along with a disengaged model of the human subject, which has a great hold on our imagination... This is one of the most prestigious forms of reason in our culture, exemplified by mathematical thinking or other types of formal calculation. Arguments, considerations, counsels that can claim to be based on this kind of calculation have great persuasive power in our society, even when this kind of reasoning is not really suited to the subject matter,

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as the immense (and I think undeserved) saliency of this type of thinking in social sciences and policy studies attests. Economics dazzle legislators and bureaucrats with their sophisticated mathematics, even when this is serving to package crude policy thinking with potentially disastrous results. (pp. 101-102)

The social sciences and policy analysis have produced a lot of information useful in the formulation of public policies in many fields, including health care. I have participated in several research and policy analysis projects designed to generate information that could be used to make more rational and beneficent policy decisions regarding services for the frail elderly. I do not think, however, that this kind of information alone is enough to develop policies that are best for the populations affected and society as a whole. We must also be prepared to address ethical issues as explicitly as possible and in as open and undistorted a manner as we can manage. The findings from social science research should be used to help construct a consensus, or at least identify points of agreement about the empirical realities of any policy subject addressed. This use of the social sciences can help create a “clearing” in which we can begin to discuss the ethical dimension of the policy issue at hand. The authors I discuss in this paper have incorporated the results of social science research into their work on ethics in precisely this manner, work that should, in my judgment, be given equal weight with the quantitatively oriented policy sciences in the formulation of health and long-term care policies for the frail elderly.

I begin with an analysis of work by Harry Moody and George Agich on the role of autonomy in long-term care policy and practice. Moody’s view is that our near obsession with individual autonomy, which is embedded in the powerful hold that individualism has over American culture, is a barrier to the development of a more humane system of long-term care. Agich is more sympathetic to the concept of autonomy, but is critical of the way the concept is used in conventional medical ethics. He calls for a more complex notion of autonomy conditioned by the realities of dependency. Later, I discuss Charles Taylor’s (1991) The Ethics of Authenticity and the work of several feminist ethicists, as summarized by Tanner, which attempts to balance versions of communal ethics with a broad recognition of the need for autonomy and individual identity in an encompassing ethic of care.

In Ethics in an Aging Society, Moody (1992) makes an important and impressive effort to use the strategies and findings of the social sciences to inform our thinking about the ethical dimensions of long-term care. In this respect, he has adopted the perspective of a leading social theorist, Jurgen Habermas, who has long practiced the art of justifying ethical standards, at least partially and however satisfactorily, on the basis of knowledge generated by the social and behavioral sciences.
I argue that autonomy is an essential condition for the sense of self(less) in modern society. Charles Taylor (1991) has described the modern era in terms of the concept of authenticity. We derive our sense of self from an original way of being. The creative sense of self appeared only in the modern era with the decline of hierarchical society and a shared sense of a divine order that characterized the premodern era. The romantic movement of the 19th century, with its emphasis on individual consciousness and sensibility, generated the framework for what Taylor calls the ethics of authenticity: the notion that one is obligated to develop the unique qualities of his/her own self. In its most popular form, this ethic has evolved into the concept of individual self-fulfillment achieved through the modalities of instrumental reason, i.e., the most efficient means to some unique source of self-fulfillment.

In Taylor's (1991) view, this is a very diminished (flattened and narrowed) concept of authenticity. It fails to recognize what Taylor calls the "horizons of significance" that make freedom (autonomy, choice) meaningful, and a sense of the "valuable" possible. An authentic sense of self and meaningful autonomy are dependent on a background of intelligibility provided by horizons of significance that emerge from the historical context and all of the interpersonal relations that constitute our immediate world. In short, an authentic sense of self is dependent on our horizons of significance, which shape choices and channel the exercise of autonomy. Horizons of significance provide part of the equation that generates authenticity. The other part is autonomy, which is grounded in horizons of significance.

Taylor (1991) claims that:

Even the sense that the significance of my life comes from its being chosen—the case where authenticity is actually grounded on self-determining freedom—depends on the understanding that independent of my will there is something noble, courageous, and hence significant in giving shape to my own life. But more: this minimum of degree of givenness, which underpins the importance of choice, is not sufficient as a horizon. It may be important that my life be chosen, as John Stuart Mill asserts in On Liberty, but unless some options are more significant than others, the very idea of self-choice falls into triviality and hence incoherence. Only if I exist in a world in which history, or the demands of nature, or the needs of my fellow human beings, or the duties of citizenship, or the call of God, or something else of this order matters crucially, can I define an identity for myself that is not trivial. (pp. 39-40)

Autonomy, then, is important because it is a necessary (but not sufficient) condition for the creation of a valued sense of self and others (mutual recognition). For this reason, it should hold a prominent place among the principles that guide the development of long-term care policy and all other policies that affect the status of vulnerable persons. From this perspective, negotiated consent (communicative ethics) and the virtues model constitute procedural safeguards designed to protect the maximum feasible exercise of individual autonomy. The preservation or expansion of autonomy should constitute the substantive content of negotiation and the goal of virtuous conduct. A rigorous adherence to the autonomy principle is necessary to avoid the slippery slope toward professional paternalism and the emergence of policies and practices that mainly serve the interests of others—i.e., convenience of family members or service providers.

Moody (1992) has made a very valuable contribution to the growing debate about the future of long-term care. He reminds us that this debate has an unavoidably ethical dimension. Long-term care policy must be guided by more than narrowly defined criteria of efficiency and cost-effectiveness and an excessively narrow focus on individual autonomy. Our capacity to improve the quality and availability of long-term care will depend on our ability to articulate values and to construct a compelling moral vision. If this is not accomplished, purely fiscal considerations and power politics will determine the future of long-term care.

In Autonomy and Long-Term Care, George J. Agich (1993) makes a sophisticated argument for autonomy as the core value governing long-term care policy and practice. His argument is based on a critique of the concept of autonomy that includes many of the same concerns raised by Moody (1992). The concept of autonomy derived from liberal theory with its heavy emphasis on individual independence, nonintervention, and rational decision-making does not provide a practical framework for an ethic of long-term care. It is too abstract and removed from the complex realities of long-term care. Like Moody, Agich's view of autonomy is grounded in a situated perspective that focuses on interpersonal relations, institutions, culture, and other contextual factors that shape the development of the self. In rejecting liberal theory's absolutist emphasis on the rights of independence and nonintervention (negative autonomy), Agich does not embrace the alternative of communalism, which emphasizes tradition rather than innovation and the community rather than the individual. Unlike Moody, he adheres to the concept of autonomy as the principle guiding value in the development of long-term care policy and in the conduct of day-to-day long-term care services.

As the basis for an ethic of long-term care, however, Agich's (1993) treatment of autonomy is complex and subject to the influence of many real-world variables that are excluded from the more conventional treatment of autonomy in liberal theory. For Agich, autonomy is more than just the power of an individual to keep others from intervening in her life without fully informed and uncoerced consent. Autonomy is also the power of an individual to interact and communicate freely with others, to give
and receive affection, and to initiate actions that are consistent with her sense of self. This positive version of autonomy is especially important in developing an ethic for long-term care. Few persons requiring long-term care services fit the liberal theory model of the fully competent, independent individual whose goal is achieving freedom from intervention by others.

For Agich (1993), this negative interpretation of autonomy is of limited utility in formulating an ethic for the care of dependent persons. He does not, however, recommend replacing autonomy in the hierarchy of values guiding the provision of long-term care. Instead, he proposes to enrich the concept of autonomy by bringing in the real world of the day-to-day life of long-term care recipients and by demonstrating how a positive notion of autonomy can shape policies and service strategies that help preserve a disabled person’s sense of self and extend the boundaries of his or her own volitional capacities. Positive autonomy means looking at the world of long-term care from the perspective of an impaired individual’s need and efforts to define and make a world that is consistent with her own identity.

Agich (1993) is not only critical of the limitations of the liberal theory ethic. He is also critical of the principles derived from the medical model of acute care, which he describes as inappropriate for long-term care. The ethic of acute care emphasizes the role of informed consent by a competent, unimpaired patient confronting relatively precise decision-making events involving specific medical procedures and short-term treatment strategies. This approach to informed consent is not an effective means of preserving autonomy in long-term care, where the lives of patients are shaped less by discrete decision-making events than by daily routines and styles of caregiving. The effective application of informed consent in long-term care is dependent on continuous, undistorted communication between the impaired persons and her care providers. Agich refers to this approach as a process model of informed consent, as contrasted with the event model of informed consent in acute care.

Agich’s (1993) emphasis on communication and negotiation reflects his intention to identify ways of protecting and expanding opportunities for autonomy in the complex “real world” of long-term care. A person’s evolving sense of self and the need to choose activities and projects consistent with her sense of self does not end with frailty and long-term care. Autonomy in long-term care is preserved by listening to and taking seriously the unique life stories of the impaired person and providing the kind of support that helps her maintain her identity despite impairment and illness. This positive interpretation of autonomy is based on the recognition of human interdependence and the limitations inherent in the liberal theory model of complete independence, especially in the context of long-term care.

For Agich (1993), autonomy in long-term care is achievable to the extent that the impaired person is able to identify with the choices she makes. She must not be forced to make decisions or adopt to conditions that negate her integrity and sense of self-worth. Long-term care, therefore, must include a broad range of options and alternatives in order to maximize the opportunities for choices and actions that are consistent with the impaired person’s sense of self and the need to maintain openings for her continued development. Even the most limited long-term care environment (nursing homes) should be designed to maximize opportunities for autonomy. This means offering supportive substitutes for the activities that the impaired person values but may no longer be competent to perform without assistance.

In his effort to identify the concrete possibilities for autonomy in the everyday world of long-term care, Agich (1993) conducts a phenomenological analysis of nursing home care, organized around the themes of space, time, communication, and efficacy. This analysis provides a framework for a critical assessment of the gap between “what is” and what “ought to be” as defined by an ethic of long-term care based on Agich’s concept of complex autonomy.

The extent to which one can move freely within and across space and time is a critical parameter of autonomy and one of the most important criteria in determining the quality of life in any long-term care setting. Drawing on literature from the ethnography of nursing home experiences, Agich claims that nursing home patients have little control over the organization and use of time in the nursing home. Time is organized to support the bureaucratic routines of the institution. The patient’s autonomy and sense of self are sharply diminished when the patient loses control over the scheduling of events and activities, which may have very little meaning to the patient anyway, given their group-oriented nature.

The loss of control over the flow of activities and the strict limitation on the array of choices a patient may have in determining how he can spend his time are not the only time-based ways in which a patient’s autonomy and sense of self may be damaged. Agich (1993) uses ethnographic findings to demonstrate that patients need to spend time with staff members talking about their lives and their perceptions of relationships between their past experiences and present circumstances. The need may frequently take the form of simply asking someone to witness, however indirectly, the patient’s suffering. The bureaucratic structuring of nursing home routines and the compartmentalizing of staff tasks, however, provide few incentives or time for this kind of intimate interaction between staff and patients.

In the absence of personalized communication, there is not much in the nursing home environment to confirm the patient’s sense of self.
Undistorted, personalized communication is a necessary condition for the effective expression of compassion and affection by staff members for patients. Agich (1993) asserts that:

Good long-term care requires an attunement to the elder so that one knows her so intimately that one immediately recognizes when she is incontinent or confused. This kind of recognition is not a matter of performing specific tasks or maintaining specialized technical skills, but involves cultivating intimate social relationships that can only be understood by reference to effectivity, which is all-too-often over-looked and undervalued as the stress on service and tasks impersonalizes care to the point where bureaucratic efficiency replaces any vestige of social or ethical significance for these basic acts of care. (p. 94)

The following passage from the concluding chapter of Autonomy and Long-Term Care summarizes Agich’s (1993) critique of the conventional concept of autonomy as expressed in liberal theory and conventional medical ethics. He concludes that efforts to apply liberal theory and acute care-oriented ethics to long-term care have left many disabled elderly (and younger adults) stranded in a moral vacuum without the resources to maintain a sense of their own humanity.

Throughout this study an expansive use of the liberal concept of autonomy and dependence and noninterference was opposed on the grounds that it is really a limited political/legal concept that is woefully incomplete for the full purposes of ethical theory. Its most notable deficiency is its failure to accommodate a concrete understanding of persons and the nature of ethical responsibilities in the everyday world. In various guises the liberal view of autonomy influences thinking about long-term care... The lack of adequate long-term care insurance... often makes illness or disability for elders an all or nothing choice: either one accepts full dependence in a hospital or nursing home because medical problems are not attended to in a timely fashion, or one struggles with the functional disabilities associated with the illnesses of being old without adequate care until disaster arrives. (p. 127)

Agich’s (1993) ethic of complex autonomy moves away from the narrow focus on unfettered autonomy inherent in the ethic of procedural liberalism and toward the situated autonomy described by Taylor (1991) in his The Ethics of Authenticity. Earlier, I quoted Taylor (1991) in defense of autonomy as a major source of individual identity in Western societies. I now want to focus on Taylor’s concept of horizons of significance that transcend the self and give meaning to the exercise of autonomy. The relationship between autonomy and horizons of significance does not lead to an ethic of paternalism. The relationship does, however, constitute a framework for an ethic of care, which is strikingly compatible with much of the work of feminist ethicists over the last several years. These ethicists have developed an ethic of care with an equal, dialectical emphasis on autonomy and dependence on others, which is, I think, the most efficacious ethical framework for the development of health and long-term care policies for the frail elderly and for assessing practice.

Taylor (1991) suggests that:

... I can define my identity only against the background of things that matter. But to bracket out history, nature, society, the demands of solidarity, everything but what I find in myself, would be to eliminate all candidates for what matters. Only if I exist in a world in which history, or the demands of nature, or the needs of my fellow human beings, or the duties of citizenship, or the call of God, or something else of this order matters crucially, can I define an identity for myself that is not trivial. Authenticity is not the enemy of demands that emanate from beyond the self; it supposes such demands. (p. 40)

Taylor (1991) is critical of contemporary notions of individualism that place little importance on ties to others. This rejection of any obligation to others is described by Taylor as the slide to subjectivism over the course of the 20th century. This slide leaves individuals with a sense of unconstrained freedom, “ready to... to indulge in an aesthetics of the self” (p. 61).

For Taylor (1991), however, authentic life involves more than the capacity to create our own identities free of social obligations and constraints. It also, “requires (i) openness to horizons of significance (for otherwise the creation loses the background that can save it from insignificance) and (ii) a self-definition in dialogue. That these demands may be in tension has to be allowed. But what must be wrong is a simple privileging of one over the other” (p. 66).

In the end, however:

... authenticity can’t, shouldn’t, go all the way with self-determining freedom. It undercut itself. Yet the temptation is understandably there. And where the tradition of authenticity falls for any other reason into anthropocentrism, the alliance easily recommends itself, become almost irresistible. That’s because anthropocentrism, by abolishing all horizons of significance, threatens us with a loss of meaning and hence a trivialization of our predicament... .

In a flattened world, where the horizons of meaning become fainter, the idea of self-determining freedom comes to exercise a more powerful attraction. It seems that significance can be conferred by choice... Self-determining freedom is in part the default solution of the culture of authenticity, while at the same time it is its bane, since it further intensifies anthropocentrism. (pp. 68-69)

The notion of self-determining freedom is closely linked to the operations of instrumental reason, which gives us the power to achieve our freely chosen desires by manipulating people and circumstances without regard for a larger moral context. But, according to Taylor (1991), instrumental reason and technical efficacy emerge from a moral context that values more than domination of nature, self-centeredness, and the manipulation of others. According to him:
Already in the early seventeenth century, Francis Bacon criticized the traditional Aristotelian sciences for having contributed nothing to relieve the condition of mankind. He proposed in their stead a model of science whose criterion of truth would be instrumental efficacy. You have discovered something when you can intervene to change things. Modern science is in essential continuity in this respect with Bacon. But what is important about Bacon is that he reminds us that the thrust behind this new science was not only epistemological but also moral.

Runaway extensions of instrumental reason have to be resisted in the name of the moral background in benevolence that justifies these applications of instrumental reason themselves. If we come to understand why technology is important here in the first place, then it will of itself be limited and enframed by an ethic of caring. (pp. 104-106)

Brenner (1994), in commenting on Taylor’s (1991) work, shows how an ethic of care informs and guides the practice of nursing. She also shows implicitly that an ethic of care has special relevance for the care of the frail elderly. Her description of nursing as guided by an ethic of care echoes Agich’s (1993) emphasis on “atonement to the elder” in a caregiving relationship. Recognition and response to the other are pervasive as nurses tell stories that depict their notions of excellence in caregiving.

... nurses talk about attending to and following the body’s lead. This is a dialogue with the particular that depends on knowing the embodied patient, and proceeding with care that sets limits on dominance and control of the body that ignores bodily responses and needs. The person’s bodily capacities and responses are given moral worth and considered a form of personhood and intentionality that require attention, respect and response. This ethical comportment preserves the status of the other as one who makes ethical claims for consideration when nursing therapies and care that alter the body’s own adaptive and recuperative powers. (p. 152)

In his response to Brenner (1994), Taylor (1994) notes that following the body’s lead is at odds with our technological bureaucratic culture which places little value on attunement to the other. Following the body’s lead also fits:

... badly into the canons of acceptable articulation, which tended... to favor ‘theoretical’ statements in general terms, preferably ‘experience-far’ ones, purged of the heat of intense personal feeling. But to do something like following the body’s lead, you have to be attuned to the patient’s self-feeling and self-description, you have to be ‘experience-near’ to the utmost. Moreover, the kind of judgment you are making is one which cannot be rendered anything like adequately in general rules. As Brenner’s study shows, sometimes the best medicine is ‘anecdotal’...

This way of proceeding brings us close to how we really understand ourselves in our ethical lives. We are incapable, lacking insight, or in the grip of a dangerous obsession, when we try to proceed without such stories in moral thinking. This means that Brenner’s work has tremendous relevance not only for understanding health care but for the whole newly burgeoning domain of medical ethics. (p. 245)

Taylor’s (1994) emphasis on narrative perspectives (stories) in these passages is similar to the approach used in life review studies of gerontology which shares this view of narrative accounts as the principle epistemological route to understanding how people identify meaning and value in their lives. These narratives can reveal “more general structures and modes of thought” through reflection. Postmodernism’s more esthetic appreciation of the narrative, however, is deeply skeptical of any effort to draw generally applicable ethical lessons from autobiographical accounts and the narrative arts. Our stories may have deeply ethical significance to us, but whether they apply to the lives of others is largely indeterminate.

Like Agich (1993) and Taylor (1994), recent work in feminist ethics has moved toward the integration of substantive (care for others) and procedural (preserving autonomy and impartial standards of justice) perspectives through our ability to connect with the narrated lives of others. Tanner (1996) has noted that this effort to transcend dualism in ethics is a result of perceived inadequacies in either perspective standing alone. Tanner states:

Isolated from one another, an ethic of either care or justice has its moral dangers. Care becomes, for example, parochial and paternalistic, justice becomes inhuman, rigid, and impossible to implement. Moral vision is advanced, feminist ethicists are beginning to argue, only when both perspectives are entertained, one by the other. (p. 175)

Dillon (1992) integrates both perspectives in her concept of “care respect.” She notes that the Kantian notion of what makes persons matter morally (their capacity for rationally autonomous moral agency) is not the only way of conceiving of persons—that the philosophical literature contains a number of themes about persons and the sources of respect for them.

The themes include the following. (1) What matters about each of us is not (only) some abstract generic capacity but the fact that we are specific concrete individuals. So, respecting persons involves responding to others as the particular individuals they are. (2) It is a morally significant fact about us that we each have our own way of looking at ourselves and the world. So, respecting persons involves coming to know them in their self-defined specificity and trying to see the world from their point of view. (3) Another of our morally significant features is that we cannot be entirely independent and self-sufficient, for we have needs and wants that we cannot satisfy on our own. So, respecting persons involves more than refraining from interference; it requires caring for them in the sense of helping them to pursue their ends and to satisfy their wants and needs. (p. 73)

One of the most fundamental criticisms of an ethic of justice, which emphasizes autonomy and impartial standards by feminist ethicists, is that it implicitly assumes “the view of nobody from nowhere” in order to achieve an unbiased, rule-based approach to resolving ethical issues and assessing ethical outcomes.

According to an ethic of care, the self is inevitably situated and constituted by relations with others (often relations of a close personal nature); an impartiality that abstracts from all this concrete relational specificity is therefore not really possible. ... Feminist ethicists replace these ineffective or inappropriate strategies for
ensuring impartiality with an open dialogue in which all bring their own highly
situated particularities of perspective and concern into a public forum for mutual
critique. (Walker, 1993, pp. 178)

Feminist ethicists do not completely dismiss the role of rules and the
points out that:

In a world infamous for its lack of caring, we need tools of persuasion to protect
the helpless. This is one of the roles that rules and rights fill. We can reason in
the language of rules with those who lack a sufficient degree of caring. If their
natural sympathies are not engaged by the presence of suffering, we can attempt
to appeal to reason: ‘How would you feel if you were in their place?’ ‘What would
be the consequence of such behavior on a large scale?’ (p. 50)

She believes that rules should provide a minimum standard for morality
and that rights can provide a minimum of protection for the vulnerable
“in the face of large-scale selfishness and inattention” (p. 51).

According to this perspective, autonomy, conceived as radical indepen-
dence in an ethic of justice, is hopelessly abstract and fundamentally
irrational in light of experience. Individuals are constituted through rela-
tions with others. On the other hand:

Most feminist ethicists do not, however, repudiate the value of autonomy insofar
as it means freedom from coercion and constraint, some control over one’s life,
and opportunities to develop one’s capacities—things commonly denied to women
in an oppressive society. Bringing these ideals of autonomy together with a rela-
tional ontology, feminist ethicists highlight the way in which people are dependent
upon one another if they are to actualize their potential—gone is the ideal of the
“self-made man.” (Manning, 1992, p. 179)

The concept of individual rights, one of the pillars of an ethic of justice,
is also revised by focusing on the relational context. An ethic of care
requires more than the negative rights (rights to be left alone, free of inter-
ference) frequently associated with an ethic of justice and its emphasis on
unfettered autonomy. An ethic of care also requires recognition of wel-
fare (positive) rights which are dependent on the nurture of others, indi-
vidually and collectively, in the pursuit of social goods like universal health
care and economic well-being. These goods cannot be achieved without
the help of others. According to an ethic of care, negative individual rights
are largely supplemental rights that help facilitate the pursuit of the more
fundamental welfare rights.

In an ethic of care, cooperation emerging from a relational context
replaces an ethic of justice focused on the regulation of “antagonism among
the self-interested,” by recognizing:

...the valid claims to attention one party may make on others: they construct
social relations by determining what one party must do for others (Minow 1990).

One also presumes that autonomy, understood as the ability to think for oneself
and develop one’s capacities, is the result rather than the presupposition of the

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rights one has; autonomy is what one has a right to expect that others will nurture
in one. (Manning, 1992, p. 180)

These feminist perspectives on autonomy and individual rights lead to
a revision of the concept of justice itself; justice revised in terms of social
relations and mutual obligations.

The idea of distributive justice predominant in an unreconstructed ethic of justice—
that is, the sense of justice as a fair distribution of social benefits and burden—is
retained here but subordinated to this substantively defined account of justice in
terms of social relations that are the opposite of exploitative, dominating, and
oppressive. (Manning, 1992, p. 180)

A just society, shaped by an ethic of care which situates autonomy in
a communal context, nurtures its members by creating conditions designed
to help members meet their needs and pursue their desires. Such a society
would be characterized by:

...mutual aid in which care-giving and care-receiving are reciprocal; the social
burdens of care-giving are shared equitably among its members. (Manning, 1992,
p. 181)

According to Joan Tronto (1994), an ethic of care should include at
least four component elements of care which she identifies as:

...caring about, noticing the need to care in the first place; taking care of, as-
suming responsibility for care; care-giving, the actual work of care that needs to be
done; and care-receiving, the response of that which is cared for to the care. From
responsibility, competence, and responsiveness. (p. 127)

She further defines these four concepts as follows:

Attention. Since care requires the recognition of need and that there is a need
to attend to the needs of others, then we cannot possibly address those needs.
(p. 127)

Responsibility. The difficulty of situating the notion of ‘responsibility’ in much of
contemporary political theory is a good illustration of the way in which contextual
moral theories differ from much contemporary moral theory. (p. 131)

Competence. To include competence as a part of the moral quality of care, is ob-
viously an approach with moral consequentialism. (p. 135)

Responsiveness. Responsiveness signals an important moral problem within care; by
its nature, care is concerned with conditions of vulnerability and inequality,...
that we are all vulnerable, and potentially equal, citizens. To assume equality
A political order that presumes only independence and autonomy as the nature of
the human life thereby misses a great deal of human experience, and must somehow
and private live. (p. 135)
Tronto (1994) thinks that these concepts have application beyond the immediate objects of our care and can be used to articulate needs and interests more broadly. She proposes that they be used as framework for political action and the formulation of public policy. She writes that:

The promising scenario of a politics of care, then, requires that we think about care in its broadest possible public framework. It requires that care’s focus on needs change the content of our public discussion so that we talk about the needs of all humans, not just those who are already sufficiently powerful to make their needs felt. It requires a recommitment to democratic processes, for example, to listening and to including care-receivers in determining the processes of care. It requires a hard look at questions of justice, as we determine which needs to meet. And it requires, on the most profound level, that we rethink questions of autonomy and otherwise, what it means to be a self-sufficient actor, and so forth. (p. 172)

Many feminist ethicists claim that we do not diminish the importance of justice by giving a notion of care equal status in a theory of ethics that recognizes the value of the contingent as well as the universal and the emotional as well as the rational features of human existence.

These revisions in an ethic of justice and, in our concept of a just society, are not trivial. Acceptance of these revisions would require qualitative changes in the conduct of day-to-day life and in our public policies. As Tronto (1994) has pointed out:

Care’s absence from our core social and political values reflects many choices our society has made about what to honor. These choices, starting as far away as our conceptions of moral boundaries, operate to exclude the activities and concerns of care from a central place. Through that exclusion, those who are powerful are able to demand that others care for them, and they have been able to maintain their positions of power and privilege.

Care is not a parochial concern of women, a type of secondary moral question, or the work of the least well off in society. Care is a central concern of human life. It is time that we began to change our political and social institutions to reflect this truth. (p. 189)

Among the changes that an ethic of care would mandate, are changes in the institutions that affect our understanding and treatment of the frail elderly. Our current policies and programs for the frail elderly are not designed to protect their autonomy and the provision of basic care is far from adequate. Most publicly supported long-term care is provided in nursing homes where patient autonomy is a low priority and the quality of care is shaped by the impersonal bureaucratic routines described by Agich (1993). In short, our treatment of the frail elderly falls far short of what we should expect under either an ethic of justice or an ethic of care. Given the current and growing emphasis on reducing public expenditures and replacing publicly administered programs with privatized alternatives, which are presumably responsive to the efficiency maximizing operations of the market, this gap threatens to widen as the huge baby boomer generation reaches their 70s in the next two to three decades.

In order to resist a widening of this gap, I think it would be useful to conduct a thorough critique of our perceptions of the elderly and our current policies and programs for the frail elderly from the perspective provided by an ethic of care as articulated in the work of Moody (1992), Agich (1993), Taylor (1991), and the feminist ethicists reviewed in this paper. Such a critique could help dispel the notion that we are doing the best we can now for the elderly in need of long-term care and the emerging assumption that in the future we will probably have no choice but to do less.

An ethic-of-care based critique could be used as part of a broader political effort to convince the public that our capacity to resolve policy issues related to health care and long-term care for the frail elderly without the means to provide fully for themselves will be affected by more than economics. There is a moral matter at stake in how we perceive and address these issues—a moral matter that is not easy to articulate in a society where the source of value is increasingly limited to market transactions (i.e., value as determined by what sells), but one that an ethic of care used to critique current attitudes, policies, and practices could help bring to full expression.

An ethic of care can guide us in finding ways of valuing the old outside of a purely productionist framework dominated by an obsession with technique and instrumental reason. There must be room in our view of life for wisdom and generosity derived from a recognition of mutual dependency and what those who go before us have to teach us about our own humanity and in whose lives we see what awaits us. I think this recognition and instruction can only occur in the context of an ethic based on more than individual autonomy and material gain. It requires an ethic of care that binds the generations, encourages sacrifice, and generates spiritual meaning.

As I said in an earlier review (1996) of Agich’s book:

Until we are able to handle the reality of dependency and recognize the fact that dependency does not end the need for autonomy, we are likely to remain uncomfortable with or even frightened by the aging process.

Cultural norms that almost exclusively value youth (the appearance of), physical health, emotional and physical independence, and the ability to shift identities and moral perspectives in response to changes in the cultural currency (what sells) are not designed to help one live well in old age. In this cultural context, significant increases in physical or cognitive dependency will all too frequently require that a frail elderly person pay what Agich calls the “full price of independence” in order to receive any help with his or her disabilities. It is as if the individual must accept a downward shift in his or her status as a human being, from fully independent and autonomous to dependent and thus without the need to exercise choice or to continue activities, however limited, that are consistent with the sense of self. (p. 76)

An ethic of care based on the work discussed in this article would recognize the need to balance the protection of autonomy with the realities...
of dependency and interdependency in the provision of long-term care for the frail elderly. A critique of current long-term care systems from the perspective of an ethic of care which incorporates Agich's concept of complex autonomy and the feminist concept of welfare rights, or what Hofland (1995) calls the "right to flourish," would discover, at a minimum, that the current system is not designed to accommodate a wide range of dependency and to maximize autonomy at every point. It would reveal the need for a flexible system of care that is responsive to individual needs, and does not impose uniform practices within hard institutional structures.

We have only begun to tap the potential of programs designed to accommodate dependency by providing resources for the exercise of autonomy. We have learned enough from our limited initiatives, however, to know how such resources can be effectively employed. Adequately funded in-home and congregate care (assisted-living) alternatives to institutional care can provide opportunities for autonomy far beyond those currently available. This is true even for those who are seriously disabled, including persons with Alzheimer's disease who should not be limited to locked units in congregate settings, but should be provided space in which to wander.

The development of these programs should not be governed by cost-effectiveness criteria only, or the effectiveness criteria should incorporate an ethic of care framework which includes an emphasis on autonomy. Just such a framework constituted the original vision for the development of the assisted living program for seriously impaired and publicly supported residents in most states. This vision featured a commitment to quality-of-life values, including autonomy, privacy and dignity and other values that are more achievable in a home like, rather than institutional environment. We should hold fast to this vision and apply it not only to the development of assisted living programs but to the entire spectrum of long-term care services as well.

In my judgement, an ethic of care of the kind described here, which incorporates rules derived from a concept of justice, can play an important role in the debate about the ethics of managed care as efforts are undertaken at the national and state levels to expand the number of Medicare recipients and the number of frail elderly receiving Medicaid-funded long-term care services in health maintenance organizations and other managed care arrangements. Most of the evaluative research conducted to date indicates that managed care does not work well for patients requiring chronic care, ([Shaughnessy, 1994] and [Ware, 1996]).

If this is true, policies designed to induce more elderly and disabled persons with chronic care needs into managed care cannot be justified in terms of an ethic of care based on Tronto's (1994) four concepts. Using these concepts as criteria in assessing these policies one could claim that they fail, in terms of attentiveness, by actually reducing the needs recognized and met in this population; in terms of responsibility, by reducing the role of government and the individual and expanding the role of proprietary providers in deciding the kinds of health care to be provided; in terms of competence, by inducing more frail elderly and disabled into service arrangements that have demonstrated deficiencies in meeting chronic care needs; and in terms of responsiveness, by increasing the vulnerability of the frail elderly to inadequate care.

Managed care has the capacity to improve the quality and availability of care for the frail elderly through the integration of services, reduced out-of-pocket costs and increased training in geriatrics. I doubt, however, that these benefits will be achieved without a full-scale debate over the ethics of managed care, which are at least as important as the economics of managed care. Moreover, a debate based on an ethic of justice alone will not be sufficient to address all of the ethical issues posed by proprietary managed care. A full-scale debate would include an ethic of care perspective and the generation of ethical criteria based on the concepts and concerns developed by Moody (1992), Agich (1993), Taylor (1991), Tronto (1994) and others who are attempting to construct an ethic informed by notions of human need and substantive values like compassion and generosity.

These are just a few examples of what an ethic-of-care based critique of the current long-term care system would reveal as serious deficiencies in the way care is now provided for the frail elderly. This sort of critique would contribute substantially to restoring our capacity to value the elderly in other than cost benefit, productionist terms.

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