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Postprint / Postprint

Zeitschriftenartikel / journal article

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Empfohlene Zitierung / Suggested Citation:

Mars, G. M., Kempen, G. I., Widdershoven, G. A., Janssen, P. P., & Eijk, J. T. v. (2008). Conceptualizing autonomy in the context of chronic physical illness: relating philosophical theories to social scientific perspectives. *Health*, 12(3), 333-348. <https://doi.org/10.1177/1363459308090052>

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Conceptualizing autonomy in the context of chronic physical illness: relating philosophical theories to social scientific perspectives

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ABSTRACT The aim of this article is to conceptualize autonomy in the context of chronic physical illness. To this end, we compare and contrast a selection of contemporary philosophical theories of autonomy with social scientific perspectives on chronic illness, particularly models of disability and symbolic interactionism. The philosophical theories mainly depart from a positive conceptualization of autonomy, which involves actively shaping one's life and identifying with fundamental values. This conceptualization is preferred over a negative conceptualization, which defines autonomy as non-interference, for its compatibility with social models of disability and with the assumption that people are interdependent. Interference may disable, but also enable people with a chronic illness to shape their lives. What matters is that people can realize what they want to realize. We suggest that, in the context of chronic physical illness, autonomy might be conceptualized as correspondence between what people want their lives to be like and what their lives are actually like. Disturbed autonomy might be restored either by expanding opportunities to arrange life or by adjusting how one wants life to be arranged. The grounds for the latter approach might be questioned, first, if people have not adjusted what they want carefully, and second, if reorganization of the material and social environment would have made it unnecessary to adjust one's arrangement of life.

KEYWORDS *autonomy; chronic illness; conceptualization*

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Introduction

Chronic physical illness may bring about pervasive changes in people's lives. For example, it may become difficult to perform valued activities and social roles, dependency on others may increase and future plans may need adjustment. Under these circumstances, it is a real challenge to preserve self-determination. People with a chronic illness continuously have to negotiate autonomy in their daily activities and in their relationships with family, friends and society (Williams and Wood, 1988).

Previous research has uncovered various threats to autonomy, such as functional decline, institutionalization, professionals' paternalistic approach, people's negative mindset and lack of clarity about goals, aspirations and purpose in life (Collopy, 1988; Hickey and Stilwell, 1992; Agich, 1993; Becker, 1994; McWilliam et al., 1994). Opportunities to promote autonomy have been suggested as well, including cognitive behavioral therapy and a patient-centered approach by health professionals (Rybarczyk et al., 1992; Williams et al., 1998).

The fact that previous research on autonomy has identified different threats and opportunities might be due to the use of different conceptualizations of autonomy. These may have different implications for research, policy and practice aimed at autonomy support. Consider, for example, the relationship between autonomy and dependence. As Berlin (1969) already has pointed out, some scholars equate autonomy with independence and non-interference, which implies that dependence conflicts with autonomy. Yet other scholars conceptualize autonomy as actively shaping life in accordance with one's own values (Berlin, 1969). Other people may facilitate this, which means that dependence may enable autonomy. Then there are scholars who argue that all people depend on others during the entire life cycle, albeit to various degrees, which means that autonomy can only take shape through this *interdependence* (Tronto, 1993). Hence, depending on its conceptualization, autonomy may be promoted or impinged on by reducing dependence.

Which of the different conceptualizations of autonomy is 'the right one' is an issue unlikely to be resolved, because who should decide this and on what grounds (Seidman, 1992)? We might, however, argue on pragmatic grounds why we favor a particular conceptualization in a particular context (Seidman, 1992). The implications of different conceptualizations of autonomy have been discussed in the contexts of different disciplines such as gerontology (Collopy, 1988), nursing (e.g. Hertz, 1996; Ballou, 1998; Proot et al., 1998; Keenan, 1999; Aveyard, 2000) and rehabilitation (Proot et al., 1998). In the context of chronic physical illness, however, the implications of different conceptualizations have not been discussed yet. It therefore remains unclear how autonomy might be understood with regard to chronic physical illness.

This article aims to conceptualize autonomy in the context of chronic physical illness. To this end, we compare and contrast a selection of contemporary philosophical theories of autonomy with social scientific perspectives on chronic illness. The philosophical theories offer a thorough debate on autonomy, while the social scientific perspectives provide a rich source of insights into living with chronic illness. Some of these philosophical theories adopt a view of human beings that has been criticized for its focus on reason and consciousness and its disregard of the social reality people are embedded in (Hall, 1992; Tronto, 1993; Mackenzie and Stoljar, 2000a). Although this criticism is deserved, we think the conceptual clarity of these theories may still help to conceptualize autonomy in the context of chronic physical illness, particularly in combination with the other theories that will be discussed.

First, we discuss the difference between negative and positive autonomy, an important classification of contemporary philosophical theories of autonomy. Next, we discuss four philosophical theories of autonomy in greater depth. The first theory (Feinberg, 1986) discusses prerequisites for autonomy, while the three other theories (Dworkin, 1988, 1989; Frankfurt, 1989; Agich, 1993; Mackenzie and Stoljar, 2000a) focus primarily on the conceptualization of autonomy. The second (Dworkin, 1988, 1989; Frankfurt, 1989) has an individualistic, psychological focus, while the third (Agich, 1993) and fourth (Mackenzie and Stoljar, 2000a) put more emphasis on social conditions and practical circumstances. We relate each theory to social scientific perspectives on living with chronic illness, particularly social models of disability and symbolic interactionism. Furthermore, we relate each theory to the case of Anne, which is described in the next section. Finally, we suggest how autonomy might be conceptualized in the context of chronic physical illness and we briefly discuss some additional critical views on this concept of autonomy.

The case of Anne

Anne is a middle-aged woman who is married and has two sons away at college. Anne worked as a head nurse at the local hospital, when she was diagnosed with emphysema a few years ago. Emphysema is a lung disease that is characterized by shortness of breath and that gets worse gradually. At first, Anne continued her job full time with the support of her colleagues, but then she got to the point where she was so tired when she got home from work that all she could do was eat and go to bed. Her husband and sons took a larger share in housekeeping, but eventually, Anne decided to work shorter hours. It was tough on her, because she had to give up her post as a head nurse. Last year, Anne's company doctor told her that she had to quit her job entirely. Anne felt pushed out and had difficulty reconciling to disability. She therefore volunteered as a counselor for people with

a terminal illness because she expected that, as a counselor, she could truly be there for patients, which she often had felt she could not when she was head nurse. Today, the positive feedback from patients and colleagues gives Anne much satisfaction and she enjoys counseling.

How might autonomy be understood in Anne's case? Is it impinged on, because she first lost her position as head nurse and then her entire job? Or is this a prime illustration of autonomy, because Anne makes her own decisions, takes initiative and finds a solution?

Negative and positive autonomy

An important classification of contemporary philosophical theories of autonomy is the distinction between negative and positive autonomy, which was first made by Berlin (1969). While negative autonomy refers to non-interference, positive autonomy refers to actively shaping one's life and identifying with fundamental values. It is about being in charge of life (Berlin, 1969).

In negative conceptualizations of autonomy, a person is autonomous if no one interferes with his/her actions. In the context of chronic illness, concerned family members who prevent certain activities or, in the case of institutionalization restrictive regulations, may impinge on negative autonomy. In the case of Anne, negative autonomy is not impinged on by working shorter hours, because no one interfered to make this happen. It is however impinged on by the eventual job loss, because the company doctor ordered this.

Since negative autonomy may be promoted by minimizing interference, it is compatible with medical models of disability, which present disability as an individual attribute, which is caused by disease and may be solved by medical intervention (Barnes et al., 1999). Furthermore, it is in line with a particular version of social models of disability, the minority group approach. This approach considers people with disabilities as a minority group whose civil rights must be protected by anti-discrimination legislation. Discrimination is an impingement on negative autonomy, because people are hindered in their actions by others (Bickenbach et al., 1999).

Generally speaking though, negative autonomy is not compatible with social models of disability because these models argue that interference may be enabling as well as disabling. In particular, social models contend that restrictions and opportunities exist side by side, because the material and social organization of the environment varies in the degree in which the needs of people with a chronic illness are taken into account (Bickenbach et al., 1999). Hence, a social model might for example reason that when Anne lost her position as head nurse her autonomy could have been preserved if her employer had assigned another head nurse to share the position with Anne part time.

In positive conceptualizations of autonomy, a person is autonomous if she actively shapes her life and identifies with fundamental values. In Anne's case, positive autonomy is impinged on because Anne does not succeed in holding down her job although she wants to work. Positive autonomy is compatible with social and socio-medical models of disability. The latter relate restrictions in activities and social participation to an interaction between person, disease and environment (e.g. Verbrugge and Jette, 1994; WHO, 2001). Hence, in this view, Anne loses her job because she has emphysema and both she and her employer do not adapt to this circumstance adequately.

Positive autonomy may be promoted by increasing people's opportunities to arrange their lives. As mentioned earlier, the minority group version of the social model wants to create equal opportunities by means of anti-discrimination legislation. Another version of the social model calls for universalizing disability policy: rather than focusing on special needs, policy should acknowledge the wide variation between people and commit to 'universal design, not merely for public buildings and transportation, but across the board for housing, workplaces and other human environments' (Bickenbach et al., 1999: 1183).

As mentioned briefly in the introduction, the difference between negative and positive autonomy is also relevant to the relationship between autonomy and dependence. Gignac and Cott (1998) distinguish four types of dependence/independence: dependence (needs and receives assistance); imposed dependence (does not need, but receives assistance); independence (does not need and does not receive assistance); and non-independence (needs, but does not receive assistance). As mentioned earlier, we might also think of people as interdependent, that is, dependent on each other, rather than distinguishing between dependence and independence (Tronto, 1993). Anne's case has elements of dependence (her colleagues and family provided assistance that Anne needed), independence (Anne does not need and does not receive assistance to do her volunteer work), non-independence (Anne did not receive the assistance she needed to keep her paid job in general and her position as head nurse in particular) and interdependence (Anne's family, patients and colleagues depend on her support, care, instructions and so on).

In negative conceptualizations, dependence, imposed dependence and interdependence are impingements on autonomy (interference), while independence and non-independence are not (non-interference). Put differently, in negative conceptualizations of autonomy, it matters whether people receive assistance and not whether they need it. If people do not receive the assistance they need, the environment may not be enabling, but what matters here is that it is not interfering either.

In positive conceptualizations, independence, dependence and interdependence are compatible with autonomy, while non-independence is not. Imposed dependency is compatible if it is self-imposed. Baltes (1996)

has called this self-regulated dependence: people accept dependence in certain domains in order to have enough energy for other domains that they value more. In other words, in positive conceptualizations of autonomy, it matters whether people get what they need.

In summary, chronic illness may impinge on both negative and positive autonomy, but the circumstances under which this occurs differ. Negative autonomy is impinged on if someone receives assistance (regardless of whether or not she needs it), while positive autonomy is impinged on if someone does not receive the assistance she needs. Generally, we would argue for a positive conceptualization of autonomy in the context of chronic physical illness, because it takes account of people's actual needs and is compatible with social models of disability and with the assumption that people are interdependent. Despite this compatibility, not all positive philosophical theories of autonomy actually discuss autonomy in a social context, as the discussion of split-level theory below will show. First, we turn to Feinberg (1986), who has presented a model of prerequisites for autonomy, which includes both positive and negative elements.

Prerequisites for autonomy

According to Feinberg (1986), people are autonomous if they display a certain blend of virtues, including authenticity, identification, initiative and responsibility for self. This condition of autonomy depends on three necessary – but not sufficient – prerequisites. First, people need the capacity to govern themselves, which is determined by the ability to make rational choices. Second, people need the right to be a sovereign authority. In order to acquire this right, the capacity to govern oneself should be above a certain threshold. Third, people need opportunities, which depend on luck according to Feinberg.

It seems that all three prerequisites for autonomy might be affected by chronic illness. First, diseases like Alzheimer's disease or stroke might affect one's capacity. In these cases, someone may not only experience difficulty in reflecting on what they want, but also in making their wishes known to others (impingement on positive autonomy). Pain or fatigue may also influence decision making. Second, the right to be a sovereign authority is at stake if people's legal capacity is questioned or if people have to submit to restrictive regulations in institutions (impingement on negative autonomy). Third, if we extend Feinberg's theory using models of disability, opportunities may be restricted as a result of disease and/or the material and social organization of the environment, which may not adequately take into account the needs of people with a chronic illness (impingement on positive autonomy).

In our example, Anne has both the capacity and the right to be a sovereign authority, but there is a lack of opportunity to hold down her job. This may be explained differently, depending on the model of disability used.

From a medical point of view, Anne might not be fit enough physically to hold down her job. Social models might focus on the efforts of Anne's employer to meet her special needs. A socio-medical model might consider not only medical and social, but also personal factors like activity accommodation and coping.

Feinberg's model does not reveal clearly in which circumstances Anne might actually be considered autonomous, because Feinberg does not specify the exact composition of characteristics that make up the condition of autonomy. Might Anne be considered autonomous because she takes initiative and responsibility for herself, first by reducing her working hours and then by volunteering as a counselor? Or might she not be considered autonomous because she does not identify with disability? The theories in the following three sections present positive conceptualizations of the condition of autonomy.

Split-level theory

Split-level theory consists of a theory of the person developed by Frankfurt (1989) and a theory of autonomy developed by Dworkin (1988, 1989).

Frankfurt (1989) bases his theory on the capacity of persons to reflect on what they want to be motivated by. This capacity leads to a hierarchical order of desires. First-order desires express what a person wants. A person can have multiple desires, which may possibly, but not necessarily conflict. Not all desires result in action. If a first-order desire leads to action, it is called an *effective* desire. For example, a person with congestive heart failure may have both the desire to take the bus to work as usual, and to travel to work by bicycle, as advised by her doctor to get regular exercise. If the person takes the bus, this is the effective desire. Second-order desires express what a person wants to want, that is, what she wants to be motivated by. They are formed through rational, reflective self-evaluation. The person in the example might decide that she wants to be motivated by the desire to travel by bike, lifting this desire to the second order.

Dworkin (1988, 1989) adds to this, stating that second-order desires do not have to be unique or attained uninfluenced, but they must undergo critical scrutiny in order to become one's own. The desires that people have are *theirs*, but not automatically their *own*. For example, health promotion programs may make people feel that they should exercise regularly, adhere to a balanced diet or quit smoking, but in order to make these kinds of lifestyle modifications second-order desires, people have to ask themselves whether these modifications are something that they really want themselves. It is crucial to autonomy that people possess 'the capacity to raise the question of whether I will identify with or reject the reasons for which I now act' (Dworkin, 1988: 15). This evaluation must occur free from subverting influences, such as manipulation or coercive persuasion. Spouses who keep on about regular exercise, and authoritarian medical professionals

who tell people to modify their lifestyle, present obstacles to an evaluation made in freedom.

Dworkin further argues that autonomy is not a mere reflective notion, but also includes the attempt to make the outcome of evaluation effective. This means that people should try to act for the reasons for which they want to act (e.g. try to travel to work by bike). Dworkin emphasizes that it is the attempt that matters, not whether people actually succeed in acting for the reasons for which they want to act. One of Dworkin's arguments is that people might otherwise realize autonomy via intuitively wrong ways. In particular, Dworkin feels that there is something wrong with scaling down second-order desires in order to become autonomous.

The issue is particularly relevant in the context of chronic illness because scaling down is exactly what may happen in response to chronic illness. Charmaz (1995) describes how people move up and down an identity hierarchy in response to the course of illness and their social situations. An identity hierarchy consists of identity goals, which represent what or who a person wants to be, strives or hopes for, either explicitly or implicitly. Moving up and down the hierarchy, people weigh different identities against each other and determine which to give up in order to retain others (identity trade-offs). Generally, deterioration in physical functioning will force people to scale down their identity goals, while an improvement in physical functioning will encourage people to scale up their identity goals. Some people are hesitant to scale down identity goals, because they underestimate their decline, find the resulting identity losses too great or have strong feelings of commitment and responsibility. Other people are hesitant to scale up identity goals, because they fear failure or relapse (Charmaz, 1995).

According to Dworkin, people who scale down identity goals are not autonomous. On closer reading, however, Dworkin seems to be particularly concerned that people might scale down second-order desires too easily in order to realize autonomy. Dworkin would have difficulty accepting that a person who has decided she wants to travel to work by bike realizes autonomy by taking the bus at the first sight of rain and then deciding that traveling by bike is not what she wants after all. However, Dworkin would probably agree that scaling down second-order desires might produce autonomy after critical self-evaluation, as is the case in identity trade-offs. For example, a person may discover that she could really use a shower when she travels to work by bike, but that there are no facilities. After carefully considering whether she really wants to travel to work by bike under these circumstances, she might decide that she would rather travel by bus.

Applying Dworkin's argumentation to the case of Anne, what Anne does is not really all that relevant in the end, as long as she does it after careful consideration. Whether she would have volunteered as counselor or protested against the loss of her job or decided that she wanted to spend

her limited energy on, say, social activities, she is considered autonomous if she identifies with the reasons for her actions.

Actual autonomy

In contrast to Feinberg (1986) and Dworkin (1988, 1989), Agich (1993) approaches autonomy as embedded in the practical, social world of everyday life. Rather than making autonomy an abstract ideal, Agich focuses on *actual* autonomy. He is critical of the idea proposed by split-level theory, that second-order desires are formed through reflective self-evaluation. According to Agich, higher-order principles (i.e. Dworkin's second-order desires) are not a top-down affair, as claimed by split-level theory, but the product of a two-way process. Higher-level principles are constructed from actual experiences and choices; they guide future actions. These actions in turn influence the higher-level principles. Rather than an end-state, autonomy should be conceived as an ongoing process: 'To be an autonomous person in the world is to develop ... as an integrative process of accommodating oneself to new circumstances and adapting those circumstances to one's unique structures of meaning' (Agich, 1993: 106).

Certainly, Agich does not deny that people might reflect on who they are or what guides them. In particular, existential crises, life transitions or sickness may bring people to consciously consider such matters. But this is not how autonomy is displayed in daily life. In daily life, people display autonomy through constant adjustment of their intentions to the opportunities and limitations encountered in their interaction with the world. A sense of self can be derived from people's actual choices, motivations and experiences, which can be expressed in terms of higher-level principles. These principles guide future action and are subject to change. Agich's point is that these principles are the product of real life, rather than critical reflection. Autonomy is an ongoing process in which people develop, express and confirm their identity in interaction with the world around them.

Agich's presentation of autonomy including accommodation and identity development shows close parallels to symbolic interactionist work on biographies (Bury, 1982; Corbin and Strauss, 1988). According to this work, people experience a biographical disruption when they are confronted with chronic illness, meaning that they can no longer rely on assumptions and behaviors that they formerly took for granted (Bury, 1982). Restoring a biography requires the fulfillment of four tasks, which occur simultaneously and interact with each other. People have to integrate the course of illness into their biography, they must reach a certain degree of understanding and acceptance of the consequences of illness, they must reconstruct their identity, and finally, they must give their biography a new direction (Corbin and Strauss, 1988: 68).

Both the symbolic interactionists and Agich assume an ongoing process, in which events and experiences in daily life may disturb people and their identities, but may then be integrated and guide future actions. In this view, then, changing higher-order principles is a valid and natural way to establish correspondence between higher-order principles and actions. In fact, from Agich's point of view, it is a *necessary* course to restore autonomy, since Agich considers accommodating to circumstances as necessary for the process of autonomy.

In Anne's case, autonomy would thus involve an adjustment of her intentions to disability. Anne would have to reconstruct her identity, incorporating disability. She actually does this by volunteering for work as a counselor, which enables her to continue to work with patients despite disability.

Relational autonomy

The developmental nature of autonomy and its embeddedness in the social world, which Agich (1993) stresses, have also been addressed by feminist scholars (Mackenzie and Stoljar, 2000a). They criticize the inherent individualism and rationalism of prevailing conceptualizations of autonomy. In contrast, they conceptualize autonomy *relationally*, aiming to express that people are not only rational, but emotional and creative as well, and that they are embedded and socialized in a social and historical context in which they depend on each other. Through social relationships and in networks, people constitute their identity and find recognition of it. Only through the social context, can autonomy take shape (Mackenzie and Stoljar, 2000b).

Unlike Agich (1993) and like split-level theory (Dworkin, 1988, 1989; Frankfurt, 1989), the relational scholars attribute a central place to conscious reflection in the realization of autonomy. However, unlike split-level theory and like symbolic interactionism (Corbin and Strauss, 1988; Frank, 1995), they contend that reflection does not necessarily have to be rational, but may also involve emotions, creativity or imagination (Friedman, 2000; Mackenzie, 2000). Symbolic interactionism too describes how people make sense of and give meaning to their lives by daydreaming, imagining and constructing stories (Corbin and Strauss, 1988; Frank, 1995). According to the relational scholars, reflection is not primarily an individual matter, but a process that takes place through interaction and communication. Autonomy thus is based upon dialogical hermeneutic procedures. This entails a view of autonomy as self-development through dialogue (Widdershoven, 1999).

In the case of Anne, relational autonomy is illustrated by the support of family and colleagues who help Anne, first, to continue her job and then to make a tough decision and give up her position as head nurse to reduce work hours. Relational autonomy is impinged on when Anne hears that she will lose her job and feels pushed out. The company doctor does not take into account Anne's circumstances and does not offer any support.

Relational autonomy requires that Anne can take account of her feelings in this difficult situation and get support from others to find a solution that fits her needs. One might question whether the situation could not have been changed in such a way that Anne would have been able to continue working at the hospital. After this phase, Anne is able to find a new way of living, in interaction with others. The position as a counselor seems an opportunity for Anne to develop herself, and the positive feedback from colleagues and patients seems to reinforce her satisfaction with the position.

Discussion

We have presented a selection of philosophical theories of autonomy in relation to the context of chronic physical illness as described by social scientific perspectives. The emphasis was on positive autonomy, although chronic illness might also impinge on negative autonomy. However, a negative conceptualization of autonomy seems unsatisfactory in the context of chronic illness because it focuses on impingements on autonomy due to interference from the environment. In contrast, a positive approach is compatible with interference provided it meets people's needs, although not all positive theories of autonomy take account of the social and practical context of daily life in which people depend on each other, as split-level theory illustrates.

Dworkin (1988, 1989), Agich (1993) and the relational scholars (Mackenzie and Stoljar, 2000a) all present positive conceptualizations of autonomy, but Dworkin focuses on an individual, psychological process, while Agich and the relational scholars focus on accommodation to the social, practical world of daily life. According to Dworkin, critical reflection on desires is the key to autonomy. Hence, as long as chronic illness does not affect the capacity to reflect, it does not threaten autonomy. Agich argues, that chronic illness may change someone's daily reality in such a way that she can no longer identify with it. Autonomy then requires accommodation to the changed circumstances.

When accommodation is difficult, Agich suggests that the circumstances might need to be changed to facilitate identity development. Likewise, social and socio-medical models of disability point out, that a restrictive material and social organization of the environment may restrict opportunities. Hence, reorganization of the environment might increase opportunities and make accommodation superfluous.

If this is so, then Dworkin is right to express his concern that people might scale down second-order desires too easily. Not because people might scale down desires without careful consideration, but rather because people might accommodate to opportunity ranges that are unnecessarily restrictive. In the case of Anne, allowing part-timers to share the position of head nurse might have enabled Anne to keep her position as head nurse while she worked at the hospital.

The importance of opportunities is recognized by Feinberg (1986), who presents opportunities as a necessary prerequisite of autonomy. Feinberg's model offers conceptual clarity, putting the condition of autonomy at the center, with capacity, right and opportunities as prerequisites. However, it also has three important shortcomings. First, it ignores the social context people are embedded in, because it presents opportunities simply as the result of bad luck. As already indicated above, this might be 'fixed' in the context of physical chronic illness by extending Feinberg's model with a model of disability. We would suggest a socio-medical model, because it considers the interplay between person, disease and environment instead of focusing on one aspect. Second, Feinberg's model narrows the capacity to direct one's life down to the ability to make rational choices, which feminist scholars, among others, have long agitated against (Mackenzie and Stoljar, 2000a). And third, it does not specify the exact composition of characteristics that make up the condition of autonomy.

The second and third shortcoming of Feinberg's model might be fixed by combining it with the theories of the condition of autonomy (split-level theory, actual autonomy and relational autonomy). In all these three theories, achieving correspondence between higher-order principles and actions appears to be the 'ultimate goal' of autonomy. However, split-level theory still has in common with Feinberg's model an ignorance of the social context and a focus on rational reflection. Also, its conceptualization of autonomy implies that autonomy requires that people know their desires. Yet this assumption has been criticized from different perspectives. Psychoanalysts, for instance, argue that persons do not know all their desires, because unconscious psychological processes may be at work. Marxist structuralist scholars argue that persons can never truly know what they want, because they are always shaped by circumstances formed by former generations. And poststructuralist scholars, for example, add to this that the meaning of an identity can never be completely fixed, as meanings in general never are, because they are expressed in language, which is a social system in which meanings arise and vary in relation to others (Hall, 1992).

These points of critique have led scholars to reject the idea of autonomous persons altogether. Alternatively, the relational scholars and Agich present conceptualizations of autonomy that meet those critiques to some extent. Relational and actual autonomy can only take shape through the social, historical environment. Furthermore, the relational scholars broaden the capacity to direct one's life from rational reflection to involve emotions, creativity and dialogue as well, while Agich argues that conscious reflection is possible but not the usual way in which principles are developed and modified. Higher-order principles are rather the product of choices and experiences in real life.

We therefore suggest conceptualizing autonomy in the context of physical chronic illness as correspondence between what people want their

lives to be like and what their lives are actually like. To achieve this correspondence, people need to develop principles expressing what they want their lives to be like. Furthermore, they need the opportunities to arrange their lives. People generally develop these principles in daily life, as they interact, make choices and gather experiences. Reflection – involving ratio, emotions, creativity, imagination or dialogue – can, however, also play a role in the process of developing and modifying principles. If chronic illness has disturbed the correspondence between what people want their lives to be like and what their lives are actually like, the correspondence may be restored either by increasing the opportunities to arrange life or by adjusting how one wants life to be arranged. The grounds for the second approach might be questioned, first, if people have not carefully changed what they want, and second, if reorganization of the material and social environment would have made it unnecessary to adjust principles about the arrangement of life.

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