

Towards a broader understanding of agency in biomedical ethics

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Abstract With advances in medical science, the concept of agency has received increasing attention in biomedical ethics. However, most of the ethical discussion around definitions of agency has focused either on patients suffering from mental disorders or on patients receiving cutting-edge medical treatments in developed countries. Very little of the discussion around concepts of agency has focused on the situation of patients suffering from common diseases that affect populations worldwide. Therefore, the most widely-used definitions of agency may be not appropriate to analyse common diseases among large populations. The branch of social sciences known as development studies draw on their own definitions of the term agency that may provide a more applicable and accurate way of referring to common and general cases than the definitions currently used in bioethics. Moreover, the psychological Self-Determination Theory may improve the usefulness of these definitions in common situations. This article explains the characteristics and the shortcomings of current bioethical definitions of agency when they are applied to common medical conditions worldwide. A new, value-based concept of agency, informed by development studies, is proposed as more accurate and useful for biomedical ethics.

Keywords Agency · Bioethics · Illness · Self-determination

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Introduction

With advances in medical science, the concept of agency has received increasing attention in biomedical ethics. New medical technology and treatments are challenging previously established ethical concepts. For example, the introduction of assisted reproductive technologies (ART) has challenged traditional concepts of *autonomy*, *informed consent*, and *reproductive rights* (Kalbian 2005).

A similar phenomenon has occurred with the development of deep brain stimulation (DBS) (Mathews 2011; Lipsman and Glannon 2012) and psycho-pharmaceutical products (Levy 2011; Singh 2013), as well as with the advances in knowledge on mental disorders (Szasz 2001; Pearce and Pickard 2010). Concepts such as *liability*, *responsibility*, *motivation* and *free will* are currently in the focus of analysis and debate. The concept of agency is frequently used to address these issues (Szasz 2001; Pearce and Pickard 2010; Edwards et al. 2011; Levy 2011; Mathews 2011; Blacksher and Lovasi 2012; Lipsman and Glannon 2012; Singh 2013).

However, these discussions frequently focus on patients undergoing newly developed medical treatments, an option generally available only to a minority of people. An example is the case of HIV/AIDS, which was an appealing topic for the mainstream bioethics community when it was an epidemiologically relevant issue for the developed world. The topic became less popular when the epidemic was controlled in the developed world, despite still being a major burden in the developing countries (Rennie and Mupenda 2008). Similarly, there is little focus on the agency of people from poorer countries or of patients around the world suffering from common conditions, such as diabetes or hypertension.

The aim of the present article is to argue in favor of a broader understanding of the concept of agency in

bioethical debates, in order to make room for common diseases and for cases with patients from developing countries. First, several bioethical meanings of agency are described. Then, the shortcomings of these definitions are illustrated by means of examples. A definition of agency used in development studies is compared with other definitions currently used in bioethics. Finally, the paper argues that the definition originated in development studies helps to overcome the shortcoming of the definitions currently used in bioethics.

Agency in bioethical literature

Different meanings and uses

The concept of agency differs across studies in biomedical ethics literature, and those diverging definitions must be examined before any attempt can be made to perform a comparative analysis. This review is not intended to be exhaustive, but to illustrate how the same concept may have different meanings within one field (see Table 1).

For some authors, agency is “the capacity for self-directed behaviour” (Blacksher and Lovasi 2012, p. 173), which is affected by perceptions of the physical environment, barriers exerting control over personal behavior, participation in processes of change, and personal preferences and values. These authors also claim that “*the notion of agency becomes important as an index of the capability and freedom to exercise choice and opportunity for change*” (Edwards et al. 2011, p. 1654). Thus, agency is a concept that must be taken into account when designing public health interventions, such as changes in the physical environment that aim to increase physical activity.

Considering people’s agency in implementing these programs not only demonstrates respect for persons, but also increases the chances of the programs’ success (Blacksher and Lovasi 2012).

Agency has also been referred to as “*the capacity to initiate and execute plans of actions*” (Lipsman and Glannon 2012, p. 468), which in turn includes motivational, cognitive, affective, and physical capacities. Linking agency to these capacities may raise concerns regarding free will, since those features have a significant role in volition (Singh 2013). Describing the interaction between agency and volition, Singh (2013) emphasizes that each one of us has a particular way of living his or her own life, according to personal identity. In this account, authenticity is defined as concordance between behavior and identity. The difficulty is that there are two different and conflicting conceptions of authenticity: self-discovery, i.e. being true to oneself and listening to the inner voice, and self-creation, i.e. creating oneself as one wishes to be (Levy 2011), which are beyond the scope of this article.

Finally, some authors do not offer an explicit definition of agency, but the link between it and control over voluntary actions is posited: active agents deploy rational behavior, i.e. they can explain their reasons for deciding to act in a certain way. The opposite situation is when people act under the force of uncontrollable impulses, as if they were “*the victim of injurious biological, chemical or physical processes acting upon [them].*” (Szasz 2001, p. 298) This perspective intends to provide some guidance regarding determining liability in cases of mental diseases, and it claims that someone lacking control over his behavior could have a decreased personal responsibility. Moreover, according to this account, the assessment of agency is a social process, in which “*an individual must be*

Table 1 Different definitions of agency

Definition	Determinants	Used in the analysis of	Limitations
The capacity for self-directed behaviour (Blacksher and Lovasi 2012)	Perceptions Auto-determination Preferences and values	Implementation of public policies, as an index of people’s freedom	Extremely focused on autonomy Neglects social dimension Difficult to appraise
The capacity to initiate and execute plans of actions (Lipsman and Glannon 2012)	Motivations Cognition Affective and physical capacities	Analyses of free will, personal identity and authenticity.	Neglects social and cultural dimensions Difficult to appraise
The capacity to control voluntary actions (Szasz 2001)	Rationality Social recognition	Determination of liability	Neglects affective dimension Difficult to appraise
The ability to act on behalf of what you value and have a reason to value (Ibrahim and Alkire 2007)	Autonomy Competence Relatedness (Deci and Ryan 2000)	Psychological well-being Effect of public policies	Not yet fully received in biomedical ethics

able and willing to function as a responsible member of society, and society must be willing to ascribe that capacity and status to him.” (Szasz 2001, p. 300) Under this definition, health professionals should “enable a patient’s agency to develop and improve their capacity for control, and help them to take responsibility for their well-being.” (Pearce and Pickard 2010, p. 832).

Challenges to the current bioethical definitions of agency

These definitions of agency, while reasonable and meaningful, are too specific and narrow in scope. Therefore, first they may be ill-suited to analyze the situation of patients suffering from common physical diseases, such as diabetes or hypertension, in which the disease has a milder effect on people’s mental capacities. Second, they also may be not sensitive to the cultural variations when addressing the situations of people from diverse backgrounds.

Although it is possible to suppose that persons suffering from severe depression may experience significant hindrances to “initiate and execute plans of actions” and patients receiving some psychotropic medications may have reduced control over voluntary actions, it is not easy to claim the same of a patient suffering from diabetes or hypertension, as may be seen when a patient states: “*I don’t let it [diabetes] run my life for me. It hasn’t really impeded what I do. I don’t automatically think ‘I can’t do that because I have diabetes’. I am much more likely to think ‘is it possible for me to do that?’ You know, if I fancy doing something, I’ll do that...*” (Small et al. 2013, p. 7). Patients suffering from many chronic diseases usually do not experience the same level of psychological perturbations than patients suffering from mental illnesses such as depression, which have been the basis for the definitions of agency previously provided. Nevertheless, chronic diseases do affect people’s sense of control, and this issue must be taken into account by bioethicists.

Moreover, concepts that have arisen from the analysis of these problems may be non-applicable to bioethical discussions of cases involving people of different values and cultural norms. The emphasis on individual control over decisions and behavior, for instance, seems to neglect social bonds and relationships, which are especially important in non-Western contexts and are being addressed by feminist bioethics, among other recent movements.

In a study from Iran, for example, the physician’s instructions and opinions were extremely important to patients, as is shown by statements such as “*I believe that my doctor is expert. Doctor tells me ‘do’ and I only respond ‘yes’*” (Abdoli et al. 2008, p. 449). The authors of this study emphasize that, even though it is suggested that

patients’ autonomy should be enhanced as a key to empowerment, these patients claimed they felt more in control of the situation because they “*put their care in the hands of their doctors and completely trusted them for medical care and support*” (Abdoli et al. 2008, p. 451). This scenario shows how patients may feel empowered by the sense of being taken good of, which seems to contradict the high value that some definitions assign to “self-directed behaviour”. Remarkably, it is difficult to appraise the capacity to “initiate and execute plans of action” of this patient, because he strictly follows external commands without questioning them.

In another study, Chinese patients suffering from cancer regained the feeling of control over their lives due to many factors, among them social support: “*Support and comfort from others is of utmost importance. This will motivate one to continue living. My friends help me; I see things from another perspective... I won’t let myself down. I have to go on functioning, do what has to be done. I get strength from my fellow patients; it is like recharging your batteries, and you have a good feeling after talking to them.*” (Mok 2001, p. 71) These statements highlight the high value that Chinese culture places on the “interdependent relationships between individuals at all levels of society.” (Mok 2001, p. 71) The relevance that the Chinese patients ascribed to social bonds may have led them to participate in activities they did not directly choose, challenging one definition’s emphasis on “control over voluntary actions” (Szasz 2001).

Moreover, the experience of disease may challenge the core values and beliefs not only of the people suffering from disease, but also of their relatives, as shown in a study exploring parents’ perspective of pediatric cardiac surgeries in Brazil. As the father of one patient stated: “*The odd thing is that even with all the care she was born seven months, she was born premature, one more to leave us like this: My God what have we done, and it left me—for being a man—a sense of guilt higher... The feeling of guilt is higher, and I was very weak at that time...*” (Salgado et al. 2011, p. 39). In this case, the father experienced a complete lack of control that was at odds with his identity as a man, increasing his feelings of guilt. This situation is even more difficult to address using bioethical definitions of agency since it does not say anything about actions, but only describes a feeling that may affect behavior.

These examples illustrate the shortcomings of the aforementioned definitions of agency. Many common physical diseases may affect people’s actions in subtler ways than the psychological conditions and treatments that have been the basis for those definitions; on the other hand, cultural and societal factors play an important role in interpreting and experiencing states of being such as health and disease, which in turn may change the meaning of

agency. These issues must be acknowledged in the definitions of these bioethical concepts, which are supposed to bring clarity to these concerns. Even though diseases are frequently discussed as abstract concepts, they do not take place in a void; they occur in people with subjective experiences and social relationships. To address comprehensively the individual and social consequences brought about by the disease process, we will turn to Marinker's conceptual framework (1975).

Disease and illness: powerlessness and lack of control

Marshal Marinker has suggested the need to distinguish between disease, illness and sickness (1975). While *disease* refers mainly to deviation from a biological norm or average, *illness* concerns the feelings and personal experiences that arise from living with a given disease, and *sickness* has a social connotation, including how the interactions between sick people and those around them are affected (Marinker 1975).

It has been described how many medical conditions could act as internal constraints and be part of the individual's experience of the disease, i.e. illness. Many patients with chronic diseases feel that the condition imposes a sense of powerlessness and vulnerability that is not necessarily related to their physical symptoms and, hence, relates to illness beyond the scope of disease (Boyd 2000; Strandmark 2004; Aujoulat et al. 2007).

Aujoulat et al. (2007) describes two different—but interdependent—dimensions of this experience: *loss of social and personal identities* and *loss of internal feeling of security*. The first dimension refers to the difficulty patients have in identifying with the people they were before the disease. This burden is also related to the inability to “*meet the demands of society, the people around them and the demands they place on themselves*” (Strandmark 2004, p. 138), which in some cases may bring about feelings such as worthlessness, mistrustfulness, shame, and low self-esteem. Second, patients also have the perception that the disease does not allow them to control their body, their emotions, the way they use their time, or their relationship with their environment. For example, one patient described his experience as “... *the feeling that you are not in control of your own life anymore, of your existence, of your future.*” (Aujoulat et al. 2007, p. 776) Although most patients do not constantly suffer from severe physical ailments, the unpredictability of symptoms, as well as having limited resources and an inability to change the situation, can result in feelings of insecurity, hopelessness, and the perception that their self-interests are threatened by their sickness (Aujoulat et al. 2007).

The perspective of other people not directly suffering from the disease but also involved in the patient's life must

be taken into account as well. For example, even though parents of sick children do not have their children's physical symptoms, they share some of the same distress and frustration with family members, as well as with the healthcare system (Gibson 1995). Their burdens can also be classified according to the model proposed by Aujoulat et al. (2007). For example, some of these feelings are focused on the individual's *social and personal identity* (i.e. how they cope with expectations imposed on them by society and themselves), while others are related to a lack of *internal security* (i.e. a lack of control over their future and emotions) (Goble 2004; Gannoni et al. 2010). This feeling of insecurity is frequently related to the instability that many diseases involve, as shown by statements such as “*we know we have a child in such a situation in which we can lose him at any time...*” (Salgado et al. 2011, p. 39). These concerns can lead to the feeling that their self-interests are threatened by their child's sickness (Gibson 1995).

Perhaps this is one of the reasons why some clinicians have described an integrated mother-and-child unit, arguing that it is impossible to describe one party without considering the other (Marinker 1975). This integrated unit may now be more accurately referred to as a parent-and-child unit since fathers are also often deeply involved in the caregiving process (Goble 2004). This unit seems to illustrate how the distinction between patients and kin is often blurred when addressing the disease experience, i.e. illness.

As has been postulated, the loss of identity and internal feeling of insecurity that are frequently part of the disease experience can lead to negative psychological consequences, such as feelings of powerlessness and lack of control. Even though they may be able to initiate and execute plans of action and deploy a self-directed behavior, they may feel that these plans do not fully express who they are (personal identity). The aforementioned definitions of agency do not take fully into account those features that make up the experience of disease, corroborating the claim that frameworks and concepts used in academic literature to analyze particular situations may not be suitable for other social and cultural contexts (Azétsop and Rennie 2010). In the search for a broader concept of agency, it is useful to investigate approaches that are used in other scientific disciplines.

A different approach to agency

Development studies

The field of development studies, a branch of economy and social sciences dealing with “*beneficial societal change*”

(Crocker 2008, p. 1), has closely examined poverty and inequality by means of different qualitative and quantitative techniques. An outcome of this work has been increasing evidence on how low socioeconomic and social status decreases individuals' ability to change their living conditions, further reducing their *power to make things happen* and their ability to intervene in the course of events (Johnson 2008). In one study, a Brazilian woman illustrated this concept, explaining the difference between rich and poor by saying, “*the rich one is someone who says ‘I’m going to do this’ and does it.*” (Ibrahim and Alkire 2007, p. 383) Another study on the Aytas tribe of Philippines, whose members suffer from chronic deprivation, found that this population accepted their social position as inevitable, espousing their concept of *talagang makanyan*, which means “*that’s just how it is.*” (Vida Estacio 2013, p. 1063) Hence, social deprivation has an impact on people’s perception of control.

These effects of poverty as inner constraints and lack of power have been summarized under the concept of *agency*, defined as “*the ability to act on behalf of what you value and have a reason to value*” (Ibrahim and Alkire 2007, p. 386), and some authors conclude that “*socioeconomic deprivation and adversity can undermine one’s sense of self and with it, one’s capacity for agency.*” (Blacksher 2002, p. 464) Drydyk (2013) describes some conditions of agency, namely that the agent performs the activity or at least has a role in performing it; that this activity has an impact on the world; that the agent chooses the activity; and that the agent deliberates on the activity in light of his values, judging it as valuable for its own sake. This is not an all-or-nothing process, but a gradual one in which people can exert more or less agency over their lives, according to their circumstances.

Valuing and the agent

Bratman (2007) and Korsgaard (2009) provide very insightful analysis of the meaning of valuing. According to Bratman (2007), agents organize *beliefs* (about the surrounding world) and *desires* (concerning possible states in that world, including own actions within this world). In order to make this organization (or hierarchy), agents undertake a process of reflection, weighting those different desires and beliefs to set priorities. Throughout this process, agents integrate previous experience and knowledge, which include social interactions and self-awareness. The outcomes of this deliberation are *plans* (organized and coordinated courses of action) and *policies* (general plans on potentially recurrent occasions). Nevertheless, in order to consider plans and policies as truly organized and coordinated, there must be some sort of consistence and coherence among them. The agent’s ability to perceive

herself as “*a temporal persisting planning agent, one who begins, continues, and completes temporally extended projects*” (Bratman 2007, p. 59) allows for the required stability. This account provides a great importance to *temporal self-awareness* for making up agency, as it is an extremely relevant determinant for establishing stable hierarchies of desires and policies.

Christine M. Korsgaard points out a different characteristic of agency (2009). According to her, if I am a self-constituting agent, I deem my activities to be “*an expression of my self as a whole, rather than as a product of some force that is at work on me or in me*” (Korsgaard 2009, p. 18). The concept of the wholeness of the agent is extremely important in her account, as it is the reference pattern to make the difference whether the act is originated from within the agent or not.

Therefore, a person acts as an agent, or exerting agency, when she values the activity she is participating in, i.e. the agent endorses it based on her high-order self-governing policies, which in turn are rooted in her temporal self-awareness. Moreover, the agent deems this action as a genuine expression of her own self.

Operationalization: the self-determination theory

One of the final objectives of development studies is that assisted people do not become mere recipients of aid programs, but engaged partners in their own development. This task cannot be achieved without a detailed characterization and measurement of the effects the social environment and public policies have on people’s agency and empowerment (Alkire 2005). In order to carry out this assessment, an appropriate way to empirically operationalize these concepts must be proposed. If physicians and bioethicists hope to encourage patients to view themselves as engaged partners in their health and not as passive recipients of medical interventions, the same approach has to be used.

Many theoretical frameworks have been used to conduct empirical analyses on poverty as an internal constraint, as well as the effectiveness of implemented policies. Among them, the Self-Determination Theory (SDT) (Deci 1971; Ryan and Deci 2000) stands out as an appealing alternative. This theory has advantages over other frameworks in that it allows for the assessment of agency across different dimensions (such as education, health, work and housing), it has been validated in different cultural contexts, and is feasible and inexpensive to apply. In addition, it allows for assessment and comparison between individualistic and collectivistic contexts (Alkire 2005) because of the particular way autonomy is conceptualized, i.e. not related to the authorship of the decision made by a given individual, but to the ownership of the activity undertaken.

To act according to intrinsic motivations, i.e. conduct an activity for its own sake, three basic psychological needs have to be fulfilled: *autonomy* (the feeling that one's personal values are reflected in one's behavior), *competence* (the feeling that one is effective in what one does), and *relatedness* (having strong, stable, and healthy personal bonds and attachment to others) (Deci and Ryan 2000). When these needs are satisfied, people tend to exert control over their activities and act according to intrinsic motivations; on the other hand, if these needs are thwarted, subjects' behavior may be less self-determined and they will undertake their tasks conditioned by rewards or punishments (Deci 1971; Ryan and Deci 2000).

The resemblances between agency and the SDT make this psychological theory an appropriate framework to empirically assess self-determination. According to the SDT, self-determination is defined as the ability to act according to intrinsic motivations (i.e. to engage in activities deemed interesting and valuable in themselves) (Deci and Ryan 2000), and agency refers to the ability of individuals to act according to their own goals (Kabeer 1999). It is reasonable to assume that people will define their own goals according to their values; therefore, the link between these concepts seems to be strong. Remarkably, none of these concepts is firmly focused on the decision-making process, but mostly on the volitional aspects related to motivations.

Due to the novel way in which agency is conceptualized in development studies and the availability of a validated methodology to assess it in practice (the SDT), it is an appealing concept in application to health analysis. Not surprisingly, there are already studies addressing patients' feeling of control and empowerment using this approach (Välimäki et al. 2004; Williams et al. 2011), lending support to its sensibility and feasibility. From these studies it is possible to claim that self-determination is a relevant factor in increasing the success of many medical interventions. According to the SDT, it could be argued that illness affects the agency of patients through the three basic psychological needs: it damages a sense of autonomy by leading to a perceived lack of control, it damages a sense of competence by leading to a perceived inability to meet the expectations one imposes on oneself, and it damages relatedness by leading to a perceived inability to meet the expectations of the social environment. Hence, patients are at risk of having a decreased agency because they have a disease experience that may affect their ability to act according to their intrinsic motivations.

There are plenty of validated scales in different languages developed using the SDT as a theoretical basis. The *Basic Psychological Needs Scale*, for instance, assesses the degree to which these needs are satisfied, enhancing people's ability to act according to their intrinsic motivations;

the *Self-Regulation Questionnaire* evaluates whether an individual's motivations for specific activities or general life dimensions are autonomous or controlled. There are also scales specifically designed to be used in healthcare, such as the *Health Care SDT Packet*, which assesses constructs derived from the SDT for different behavioral modifications, namely smoking cessation, diet improvement, regular exercise and responsible drinking, among others.¹

“Agencies” and autonomy

Similarities and divergences

As was commented earlier, illnesses decrease the sense of control and perceived ability to meet self-expectations across many different cultural contexts and have an impact on those not directly affected by the disease. These feelings are detrimental to individuals' sense of autonomy, competence and relatedness; therefore, it can be argued that these people not only suffer from the disease, but also from the disease experience that affects their psychological self-determination. As self-determination is a proxy for agency as defined in development studies (Alkire 2005), it follows that these individuals may have a low sense of agency. In order to avoid confusion, the meaning of agency as defined in development studies will be called *value-based agency*, while the bioethical meaning will simply be referred to as *agency*.

Among the most noteworthy divergences between the different definitions of agency and value-based agency are the scenarios in which those definitions are used. Usually, bioethical literature cites examples of patients who have very significant variations in the way agency is expressed, such as patients completely lacking agency as a consequence of severe mental diseases (Szasz 2001; Pearce and Pickard 2010) or deploying a completely new set of interests and thoughts as a consequence of a given treatment (Lipsman and Glannon 2012); value-based agency, on the other hand, deals with more subtle quantitative variations. However, this is not very significant issue when appraising the conceptual similarities between these meanings of agency since they are mere illustrations.

The second difference is much more relevant: in some accounts, agency is linked to *self-directed behavior*, and it is closely connected to the decision-making process and people's choices (Blacksher and Lovasi 2012), as is the case in bioethical autonomy. However, while autonomy is linked with *self-governance* (Beauchamp and Childress

¹ For a complete description of these and other scales, see <http://www.selfdeterminationtheory.org/questionnaires/>.

2013) and is strongly centered on people making their own choices, value-based agency addresses people's motivations, values and identity. Even though it is arguable that self-governing people act following their values and motivations, this is not always the case. For example, it has been described how economic incentives make people more prone to opt for the encouraged behavior, while decreasing the intrinsic value they ascribe to it, i.e. their actions have a weaker correlation with their intrinsic motivations (Deci 1971). By contrast, people may deem activities they are taking part in as interesting in themselves and, therefore, they are acting according to their intrinsic motivations, even though they did not make the choice to do so (Bao and Lam 2008). Hence, it cannot be claimed either that people acting with low value-based agency are in every case less autonomous, or that non-autonomous people always have lower value-based agency. Therefore, value-based agency is not merely focused on the authorship of the decision, but on the feelings that a person has regarding his or her behavior.

Nevertheless, the convergences between value-based agency and the two latter bioethical definitions of agency are significant (see definitions in Table 1). A remarkable similarity is that motivations play an important role in value-based agency and in some concepts of agency. As illustrated, the volitional and cognitive aspects related to agency provide relevant insights into people's identity (Levy 2011); in the same sense, value-based agency links actions and personal values, establishing that within a self-determined personal behavior and values are consistent.

Another similarity is that, in one account at least, agency is related to *control over voluntary actions* (Szasz 2001; Pearce and Pickard 2010), including the ability to accomplish a given task, appraise the situation, and plan further steps. These characteristics overlap in the bioethical definition of agency and value-based agency since the latter is determined by competence (similar to the ability to accomplish, present in the biomedical definition) and autonomy (which resembles aspects of planning according to one's goals, in the bioethical account). Moreover, the third determinant of value-based agency is relatedness, which is also covered by this bioethical definition of agency. As discussed before, agency is a social process, and it could be argued that someone succeeding in it would experience an adequate psychological relatedness.

As can be seen, there are strong connections between some accounts of agency and value-based agency. Nevertheless, these accounts of agency tend to be focused on specific aspects, such as control and planning, leaving aside personal, societal and cultural dimensions. Value-based agency could have a richer and more comprehensive perspective of the subjective dimension of illnesses to solve ethical dilemmas in the developing world than the

autonomy-based bioethics extensively used in Western societies (Azétsop and Rennie 2010) since it is not focused only on people's decisions, but feelings and perceptions; moreover, it provides a significant basis for evaluating agency in the context of other factors, such as social bounds.

The shortcomings of the traditional concept of autonomy have also been highlighted by the proponents of relational autonomy. According to a number of authors, autonomy must take into account that "*people are integrally connected with a social environment marked by economics, politics, ethnicity, gender, culture, and so on. Their identity is formed and shaped by their social environment, as well as their experiences of embodiment, interaction with others, and possibilities for a good life*" (Ells et al. 2011, p. 86). Relational autonomy does not only consider social environment as a fundamental factor of personal identity, but also temporal dimension (Baumann 2008). Hence, relational autonomy includes similar features than value-based agency.

The examples provided in a previous section may illustrate how these concepts enlighten the analysis: the agency of the patient suffering from diabetes is not affected by the disease (Small et al. 2013), because he feels autonomous and competent in adjusting his life goals to the restrictions imposed by diabetes; the Iranian patient feels that his agency is fostered by following the instructions of healthcare professionals because he relies on social support (Abdoli et al. 2008), which encourages him to overcome his fears; similarly, relatedness also explains why Chinese patients feel their agency is increased when they speak and interact with their relatives and other patients (Mok 2001); finally, we can better understand the Brazilian father whose agency is compromised by the disease that imposes on an identity he truly values: his role as a man and father (Salgado et al. 2011).

Conclusion

Current bioethical definitions of agency are suitable for the analysis of specific scenarios, such as DBS and psychopharmaceutical products. Nevertheless, due to their conceptual narrowness, these definitions fail to comprehensively address the effects that diseases have on people's agency in more frequent cases, such as hypertension or diabetes, or in cases of patients and their families from non-Western cultural backgrounds from which the standard concepts of agency have emerged. Furthermore, those definitions are theory-grounded and they do not have validated tools to appraise people's agency in the real world.

In development studies, agency is defined as the "*ability to act on behalf of what you value and have a reason to*

value.” With this account, it is feasible to address cases of patients suffering from common conditions, and it is also possible to analyze the situation of people from different cultures, making room for very relevant aspects of agency as valuing and identity. These dimensions are taken into account by some authors working on relational autonomy, however development studies offer a validated theoretical framework appropriate for conducting empirical assessment of people’s agency, namely the SDT, which make this concept applicable to clinical practice.

Value-based agency should receive careful attention from the bioethical literature, through empirical studies and following further conceptual analysis.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

References

- Abdoli, S., et al. 2008. The empowerment process in people with diabetes: an Iranian perspective. *International Nursing Review* 55: 447–453.
- Alkire, S. 2005. Subjective quantitative studies of human agency. *Social Indicators Research* 74: 217–260.
- Aujoulat, I., O. Luminet, and A. Deccache. 2007. The perspective of patients on their experiences of powerlessness. *Qualitative Health Research* 17: 772–785.
- Azétop, J., and S. Rennie. 2010. Principlism, medical individualism, and health promotion in resource-poor countries: can autonomy-based bioethics promote social justice and population health? *Philosophy, Ethics, and Humanities in Medicine* 5: 1–10.
- Bao, X.-H., and S.-F. Lam. 2008. Who make the choices? Rethinking the role of autonomy and relatedness in chinese children’s motivation. *Child Development Research* 79: 269–283.
- Baumann, H. 2008. Reconsidering relational autonomy. Personal autonomy for socially embedded and temporally extended selves. *Analyse & Kritik* 30: 445–468.
- Beauchamp, T.J., and J.F. Childress. 2013. *Principles of biomedical ethics*, 7th ed. New York, NY: Oxford University Press.
- Blacksher, E. 2002. On being poor and feeling poor: Low socioeconomic status and the moral self. *Theoretical Medicine* 23: 455–470.
- Blacksher, E., and G.S. Lovasi. 2012. Place-focused physical activity research, human agency, and social justice in public health: Taking agency seriously in studies of the built environment. *Health Place* 18: 172–179.
- Boyd, K.M. 2000. Disease, illness, sickness, health, healing and wholeness: exploring some elusive concepts. *Journal Medical Ethics: Medical Humanities* 26: 9–17.
- Bratman, M.E. 2007. Valuing and the will. *Structures of agency*, 47–67. New York: Oxford University Press.
- Crocker, D.A. 2008. *Ethics of global development*. New York, NY: Cambridge University Press.
- Deci, E.L. 1971. Effects of externally mediated rewards on intrinsic motivations. *Journal of Personality and Social Psychology* 18: 105–115.
- Deci, E.L., and R.M. Ryan. 2000. The “What” and “Why” of goal pursuits: Human needs and the self-determination of behavior. *Psychological Inquiry* 11: 227–268.
- Drydyk, J. 2013. Empowerment, agency, and power. *Journal of Global Ethics* 9: 249–262.
- Edwards, I., et al. 2011. Moral agency as enacted justice: A clinical and ethical decision-making framework for responding to health inequities and social injustice. *Physical Therapy* 91: 1653–1663.
- Ells, C., M.R. Hunt, and J. Chambers-Evans. 2011. Relational autonomy as essential component of patient-centered care. *International Journal of Feminist Approaches to Bioethics* 4: 79–101.
- Gannoni, A.F., and R.H. Shute. 2010. Parental and child perspectives on adaptation to childhood chronic illness: A qualitative study. *Clinical Child Psychology and Psychiatry* 15: 39–53.
- Gibson, C.H. 1995. The process of empowerment in mothers of chronically ill children. *Journal of Advanced Nursing* 21: 1201–1220.
- Goble, L.A. 2004. The impact of a child’s chronic illness on fathers. *Issues in Comprehensive Pediatric Nursing* 27: 153–162.
- Ibrahim, S., and S. Alkire. 2007. Agency and empowerment: A proposal for internationally comparable indicators. *Oxford Development Studies* 35: 379–403.
- Johnson, D.P. 2008. Human agency, the structuration process, and social systems: Linking micro, meso, and macro levels of analysis. *Contemporary sociological theory: An integrated multi-level approach*, 459–489. New York, NY: Springer.
- Kabeer, N. 1999. Resources, agency, and achievements: reflections on the measurement of women’s empowerment. *Development and Change* 3: 435–464.
- Kalblian, A.H. 2005. Narrative artifice and women’s agency. *Bioethics* 19: 93–111.
- Korsgaard, C.M. 2009. *Self-constitution; Agency, identity and integrity*. Oxford: Oxford University Press.
- Levy, N. 2011. Enhancing authenticity. *Journal of Applied Philosophy* 28: 308–318.
- Lipsman, N., and W. Glannon. 2012. Brain, mind and machine: What are the implications of deep brain stimulations for perceptions of personal identity, agency and free will? *Bioethics* 27: 465–470.
- Marinker, M. 1975. Why make people patients? *Journal of Medical Ethics* 1: 81–84.
- Mathews, D.J.H. 2011. Deep brain stimulation, personal identity and policy. *International Review of Psychiatry* 23: 486–492.
- Mok, E. 2001. Empowerment of cancer patients: from a chinese perspective. *Nurse Ethics* 8: 69–76.
- Pearce, T., and H. Pickard. 2010. Finding the will to recover: philosophical perspectives on agency and the sick role. *Journal of Medical Ethics* 36: 831–833.
- Rennie, S., and B. Mupenda. 2008. Living apart together: reflections on bioethics, global inequality and social justice. *Philosophy, Ethics, and Humanities in Medicine* 3: 25.
- Ryan, R.M., and E.L. Deci. 2000. Self-determination theory and the facilitation of intrinsic motivations, social development, and well-being. *The American Psychologist* 55: 68–78.
- Salgado, C.L., et al. 2011. Pediatric cardiac surgery under the parents view: A qualitative study. *Revista Brasileira de Cirurgia Cardiovascular* 26: 36–42.
- Singh, I. 2013. Not robots: children’s perspectives on authenticity, moral agency and stimulating drug treatments. *Journal of Medical Ethics* 39(359–366): 2.
- Small, N., et al. 2013. Patient empowerment in long-term conditions: development and preliminary testing of a new measure. *BMC Health Services Research* 263: 1–15.

- Strandmark, M. 2004. Ill health is powerlessness: a phenomenological study about worthlessness, limitations and suffering. *Scandinavian Journal of Caring Sciences* 18: 135–144.
- Szasz, T. 2001. Mental illness: psychiatry's phlogiston. *Journal of Medical Ethics* 27: 297–301.
- Välämäki, M., et al. 2004. Self-determination in surgical patients in five european countries. *Journal of Nursing Scholarship* 36: 305–311.
- Vida Estacio, E. 2013. Health literacy and community empowerment: It is more than just reading, writing and counting. *Journal of Health Psychology* 18: 1056–1068.
- Williams, G.C., et al. 2011. Physical wellness, health care, and personal autonomy. In *Human autonomy in cross-cultural context: Perspectives on the psychology of agency, freedom and well-being*, ed. V.I. Chirkov, R.M. Ryan, and K.M. Sheldon, 133–162. New York, NY: Springer.