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From solidarity to autonomy.

Towards a redefinition of the parameters of the notion of autonomy

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Abstract:

Starting from examples of concrete situations in France, I show that autonomy and solidarity seem to be able to coexist only under the condition that the parameters of autonomy are redefined. I show on the one hand that, in situations where autonomy is encouraged, solidarity nevertheless remains at the foundation of the practices and, on the other hand, that in situations largely infused with family solidarity, the latter may put individual autonomy in danger. Yet, based on my ethnographic observations regarding clinical encounters and medical secrecy, I show that while solidarity may be seen to endanger *individual* autonomy, it does not necessarily endanger autonomy itself. The social practices observable in France reflect the reality of an autonomy that goes beyond the individual, a reality that involves a collective subject and includes solidarity. The opposition between these two values can then be resolved once we agree to consider that the content of the notion of autonomy is dependent on its cultural context of application and on its social use.

Keywords: individual autonomy, individual/collective, pathogenic solidarity, clinical encounter, medical secrecy, family autonomy.

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As Ruth Horn and Marie Gaille underline in the introduction of this issue, the respect of autonomy is the leading principle of Anglo-saxon health care and ethics, while solidarity tends to be more dominant in the French and continental European discourse. The Anglo-saxon tradition places more importance on respect for patient autonomy while the French perspective gives preference to the sense of solidarity. It is however clear that autonomy as a value is now becoming more widespread in France too. Under these circumstances, the question may arise as to whether these two notions are conflictual to the point that one dispels the other, or whether they are compatible so that the two can easily be reconciled in an equilibrium based on the desire to best provide for the benefit and well-being of the patient.

To answer this question, I will try to show that these two notions seem to be able to coexist only under the condition that the contours of autonomy are redefined – i.e. that the line delimiting the semantic perimeter of this notion is moved – and that this coexistence thus seems to depend on the contents ascribed to the notion. The vocation of anthropology is not to make normative propositions based on ethical choices. However, anthropology can contribute to ethical reflection by analysing practices and the social, cultural, legal and institutional context in which they take place. To contribute to this reflection, I will not enter the bioethical debate to defend or criticise the primacy

of one value or the other. Instead, I will focus on concrete practices, as observed in France among social actors, in response to the legislation, and to their own ethical or therapeutic motivations. More precisely, I will use some examples of concrete situations in the field of healthcare to investigate the link between these two notions in social practices. As a starting point, I will take two generally accepted definitions of these notions. I understand solidarity in the sense of ‘relationships between people that lead to the moral obligation for some to provide assistance to others’, and I understand the notion of autonomy in the sense of ‘the right of an individual to freely determine the rules to which he/she is subject’. Autonomy would characterise a state of patient empowerment; and solidarity would apply in particular to patients in a state of vulnerability, linked to their illness.

If we consider these two meanings, it is immediately obvious that one of the distinctions made between these notions partly hinges on the distinction between the collective and the individual. In this regard, the field observations I have made during two different research projects [9] [10] seem to confirm greater prioritisation of the collective in the French tradition and greater emphasis on the individual in the Anglo-Saxon tradition.

Between the individual and the collective

A first example is drawn from research I undertook in the past into the way alcoholism is managed by an association of former drinkers, *Vie Libre* (Free Life) [9]. Then, I tried to uncover the difference in how the phenomenon of alcoholism was considered and managed by *Vie libre* compared with *Alcoholics Anonymous*, since they appeared to be the paradigmatic representatives of this type of association. Both organisations operate in France, although the former was founded in the US and the latter in France. Yet, these two associations consider the role of the individual and his/her family in a totally different way. The Alcoholics Anonymous believe that spouses and children should not interfere in the management of the problem; if need be they meet separately (through the peripheral associations, AlAnon for spouses and partners and AlAteen, for the children) [1]. Alcoholism is the suffering person’s business and they should manage the problem on their own. The alcoholic’s family need not practice abstinence from alcohol because this only applies to the alcoholic, the only person concerned with the problem. In contrast, the *Vie Libre* movement includes former drinkers *and* their spouses or partners, who are given great importance for the support they can provide to drinkers. Alcoholism is perceived as a collective problem and the cause of a collective suffering, and spouses are recommended to abstain from alcohol too, in solidarity, in order to help the drinker recover and stabilise. For an individual illness, an individual solution; for a collective illness, a collective solution [9]. These two conceptions of the conditions of recovery are underpinned by cultural differences, partly inspired by religion. The AA was born in an Anglo-Saxon society and was greatly inspired by the Oxford Group, an English theological movement; while *Vie Libre*, although non-denominational, was created in France at the initiative of a former chaplain of the JOC (Young Christian Workers) who played an important training role for many syndicalist activists.

A second example concerns behaviour in medicinal consumption. My study of the relationships with medicines, prescriptions and doctors in different cultural groups in France [10] showed that individuals of Protestant origins made a more individual use of medicines (whether these are prescribed or taken as self-medication), and that those with Catholic origins used them more collectively. For example, there is a greater tendency to seek advice and share medicines within families of Catholic origin, while people with Protestant origins tend to consider a medicinal treatment as a personal matter. This phenomenon can be correlated with attitudes during consultations, to which Catholic people come more often in couples with one spouse accompanying

the other¹, and where the accompanying spouse (generally the wife) has no qualms in suggesting the doctor prescribe her husband a certain medicine that has worked well for her. However this practice is rarely observed amongst Protestants, who come less often in couples to the doctor's, both for reasons of discretion and to allow the patient to freely manage their own relationship with the doctor and their medical care. The opposition between individual use *versus* collective use of medicine is thus coupled with the opposition between autonomy and solidarity.

In these two situations, these pairs of opposition (between collective and individual on one hand, and solidarity and autonomy on the other) refer as much to, if not more to, *cultural* traditions (partly rooted in religion) as to *national* traditions. The solidarity in question here, which is expressed through medicinal advice or by accompanying the patient, corresponds to what can be qualified as 'private solidarity' as opposed to 'public solidarity' [26]. Nevertheless, the individual/collective opposition cannot always be superimposed onto the autonomy/solidarity opposition. Moreover, while differences exist between national or cultural traditions, they cannot be perceived in a fixist way since no tradition ever remains static especially in the context of the globalisation of values. Among the prominent values in the field of health in France today, we find in fact the promotion of both autonomy and solidarity.

Autonomy

The value of autonomy is also beginning to be widely recognised in France, under the joint effect of the influence of Anglo-Saxon ideas, and of what is called 'health democracy', which emphasizes patient autonomy, particularly since the introduction of the law of March 2002, known as 'the law on patient rights'². Autonomy is in fact increasingly valorised in the field of health [18]. It is promoted in particular in the management of chronic illnesses where autonomy is encouraged as a necessary condition for patient cooperation and the provision of appropriate care. The valorisation of autonomy is also an important element in the discourse promoting self-medication both from the health authorities and the public authorities, who (although mainly for economic reasons) believe in the development of self-medication in France, and seek to promote this practice with the lure of patient 'autonomy' [11].

As regards self-medication, the medicinal knowledge an individual gathers is fed by multiple sources (friends, colleagues, neighbours, association members, Internet), and above all by family members, to the point that the experiences of close family are liable to become substitutes for personal experience. As we have seen, family solidarity in the domain of medicinal consumption can lead an individual to advise, or even provide, a certain medicine to a family member. However, this solidarity can sometimes be problematic in that it can result in harmful care or advice (as illustrated by the case of a woman whose difficulties in getting to sleep led her mother to recommend she take an anxiolytic of the benzodiazepine family as a hypnotic – as she herself does to treat insomnia – because one of its adverse effects is drowsiness [11, p. 63]).

One noteworthy aspect however, for the present reflection, is that the discourse extolling patient autonomy to promote self-medication ignores the important distinction that exists between 'self-medication' and 'family medication'. What is being played out here refers to the distinction between autonomy and solidarity. A frequent confusion is made between these two notions ('family

¹ An interesting point in this regard is that, in French, the word "*accompagnement*" can mean both accompaniment and support.

² cf. Loi n° 2002-303 du 4 mars 2002 relative aux droits des malades et à la qualité du système de santé: <https://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000000227015&categorieLien=id>.

medication' and 'self-medication') by the health and public authorities [4], but the difference between them should however be made clear. With 'family medication', the emphasis is placed on the role of the family (domestic choices as opposed to professional or expert decisions), while 'self-medication' refers to the personal choices made by the individual, whose opinions may be influenced by his family but are not necessarily in line with those of the other family members. Moreover, self-medication can sometimes be a private activity, practiced by the person in secret in order to avoid worrying her family or to avoid the risk of being pressured into consulting a doctor when a family member learns about the symptom or health problem.

So, despite the common conflation of these two notions, it should nevertheless be recognized that it is not the same thing to decide to take a medicine by oneself, or to recommend a medicine to a family member, even if the two are not exclusive. While in both cases the subject is enacting a form of autonomy in that the decision is taken without a prescription or even without the advice of a medical authority, the second primarily results from the goal of solidarity.

Of course, individuals are never totally independent: they are exposed to a thousand different influences, including pressure from the family who transmits their own values and norms [23]. In this regard, the impact of the advice provided by family and friends is extremely variable. It is affected by the degree to which the subject credits this person's opinion which depends on his place in the kinship network and on the relationship the subject has with him. Do these influences, and especially the solidarity the subject benefits from, endanger his autonomy? To answer this question, I will examine other situations that will enable me to reconsider the relationship between solidarity and autonomy in a wider sense.

Family solidarity

The literature on patient support provides evidence of 'private' solidarity and the support role undertaken by the family [3]. The role of the family in caring for illness has been widely demonstrated by social scientists whose work has highlighted its function as both first and last resort [14], the division of care work between families and health professionals [5], and the production of family bonds during health events [6].

There is a growing interest today in family support activities in the field of health, revolving around the notion of *care* which, in opposition to *cure* (professional, technical, related to the notions of expertise and competence), refers to domestic or family work and to notions of solidarity and support [25] [27]. In many countries, the public authorities do indeed recognise the family's role in providing support and solidarity. The government of Quebec, for example, defines the family as: 'the parent-child group united by multiple and varied links, who support each other reciprocally during a lifetime and promote the development of people and societies at their source' (cited by Fortin [14] p.948).

Thus, social scientists generally consider the family as able to provide first rate social support for the individual, and in particular to assist her with an illness. From very early on, anthropologists have been interested in the family since a great number of traditional societies are structured on kinship [7] [21]. African societies are notably organised around the opposition of older and younger. The terms of this opposition relate to relationships that are, all at once, biological, social, economic, political and familial. In this framework, illness is indissociably thought of both as an individual and a collective event, and the family is primarily concerned by its occurrence since the diagnosis implicates, by means of 'explanatory models' [20], events that effects the whole family or a member of the ill person's family [8]. As such, the cure itself is a family affair. Various studies

have brought the family to the forefront in what happens for the individual when faced with an illness, and have highlighted the fact that this illness becomes a collective experience.

This phenomenon is also given prominence today in Anglo-Saxon countries even though it is not expressed as the foundation of public policy as it is in France [26]. It is sufficiently present in everyday practice for the social sciences to have taken notice. The many studies on care [24] [25] [28] demonstrate the support activities undertaken by close family, in view of providing solidarity.

A pathogenic solidarity

Although in some situations the presence of friends or family can be of indisputable help to ill people (in various ways: taking control, providing protection, comfort, practical help, etc. [16]), the family can sometimes play an ambiguous, if not harmful, role. Family solidarity can in fact produce detrimental effects for patients – in the management of their care provision and the exercise of their autonomy. Observing doctor-patient relationships and consultations as places where the two parties meet and communicate allowed me to note that the family solidarity expressed there can form an obstacle to patient autonomy [12]. It seems that here this could be named a socially pathogenic solidarity, in the sense that it may put individual autonomy in danger. To support this argument, I will examine two situations: one concerning clinical encounters and the other concerning medical secrecy, as observed in France. This allows us to get a better understanding of these ambiguities and note that beyond the support role that the family is expected to play, it also sometimes acts as a limit, constraint or obstacle.

The clinical encounter

The support or presence of a family member at a medical consultation is a valuable form of help for a patient dealing with a serious illness and the help provided in this way is crucial for cancer patients. This has been highlighted, for example, by the studies on proximology [19]. However, observing consultations and studying communication between doctors and patients showed that family members sometimes behave in ways that can disrupt this communication. Indeed, when a patient is questioned about his/her condition and the persistence or not of certain pains or other symptoms, it is not unusual for the person accompanying him/her (parent, child or spouse) to try to overplay – or underplay – the symptoms described by the patient, correcting the information provided. The intervention of a close family member in the dialogue between the patient and his/her doctor interferes in their communication, especially since the doctor is not always aware that the discourse concerning the patient's symptoms does not always originate with the patient him/herself. The family member taking part in the consultation often assumes the role of counterpoint – correcting, qualifying, confirming or contradicting the information given by the patient. This leads the family member to influence or affect patient care, for instance by hampering or prompting the prescription of additional tests or medicines.

Therefore, in the context of the clinical encounter, family solidarity - formalised here by an accompanying family member becoming involved in the patient's care - is not only likely to 'parasitise' the doctor-patient exchange by intruding with a contradictory discourse, but it is also likely to lead to the subject losing a part of his/her autonomy in so far as this autonomy is diluted in the family management of the medical relationship.

The patient and medical secrecy

One Article (L1110-4) of the Public Health Code states that ‘every person managed by a professional, an establishment, a healthcare network or any other organisation participating in prevention or care provision, has the right to respect for his/her private life and to secrecy of information concerning him/her’³. Nevertheless, while it reaffirms patient autonomy, the law on medical secrecy contains some ambiguity and has an ambivalent effect on the practices enacting this autonomy. Indeed, although secrecy covers all the information concerning the person, the Article L1110-4 also provides that in the case of a serious diagnosis or prognosis, close family members can receive the necessary information in order to allow them to support the patient, except if the patient does not assent to this.

Besides, despite the obligation of medical secrecy, health professionals frequently provide the family with information concerning the patient’s state of health, even while sometimes withholding this information from the patient him/herself. It is hard to imagine a patient being asked: ‘Do you give your permission for the doctor to reveal facts to your family that are not disclosed to you?’ (This cultural difference is doubtless more marked in other countries such as Italy, where, in the domain of oncology, the family is much better informed that the patient on the state of the latter’s health [15]). It is as if the family is not an Other or a third party to whom this secrecy would apply, and as if the family enters into a state of fusion with the patient to the point of no longer being defined as a third party to whom personal information cannot be disclosed.

This state of fusion is however only partial since the family can be provided with a piece of information that has not be disclosed to the patient himself [12]⁴. The fact that the family can be informed of issues concerning the patient by people other than the subject him/herself is a problematic situation in contemporary society, and runs contrary to the spirit of the law on patients’ rights of 2002. Here, there is an intrusion by the family, based on the principle of solidarity.

The subject and the family: between autonomy and fusion

The relationship between the individual and his/her family group affects in a complex way the position of the former vis-a-vis the latter in the social sphere. This position situates the individual as an autonomous being, but also in a state of fusion with the collective that is his/her family. This phenomenon raises the question of how to define the notion of autonomy and its links with the notion of the individual, in so as far as autonomy is only conceived of - at least in theory - in connection with the singular entity that is the human being, in this case the patient. In fact, the notion of autonomy is a cultural construction. For example, it does not hold the same meaning in Asia and in the West. According to Macklin [22], there exist cultural configurations that may be

³ Conversely to the provisions of the law n° 2004-800 of 6th August 2004 on bioethics, according to which the doctor should inform the next of kin of any serious genetic anomaly diagnosed during an examination of the genetic characteristics of a person, considering the risk non-disclosure would present to the members of his/her family, who may be directly concerned once preventative measures or treatment are proposed to them.

⁴ It is possible that the division of care work between health professionals and families encourages the former to pass the burden of disclosing bad news on to the latter.

concerned with protecting autonomy but are not rooted in the cultural value of individualism. This is the case in societies where autonomy involves family determination and not individual self-determination as in the West. Thus, in South-East Asia, it is the family that constitutes the autonomous social unit and the doctor cannot act against that [13].

Under close examination, the question arises as to whether, in the West, and in France in particular, autonomy is always perceived as individual self-determination. The practice that consists of breaching confidentiality or divulging secrets by informing the family – without the subject knowing – draws its logic from an equivocal acceptance of the notion of autonomy, or from an illusory claim as to the individual character of this autonomy.

Conclusion

In the situations described above where autonomy is however encouraged, solidarity nevertheless remains at the foundation of the practices where autonomy is actualised. Behind the application of the principle of autonomy thus lies that of the principle of solidarity. Solidarity remains solidly anchored to the point of endangering individual autonomy. But can we, for all that, say that it is endangering autonomy?

At the intersection of these two values (autonomy and solidarity) we can find the values of protection, beneficence and vulnerability. It is in order to protect the patient that *autonomy* must be guaranteed [2], but it is also to protect the patient, that *solidarity* must be guaranteed. In these conditions, there is no antinomy or incompatibility between the two, at least as regards their purpose. However, as we have seen, the social practices observable in France reflect the reality of an autonomy that goes beyond the individual subject. An autonomy that could be conceived as collective. The tension – if not the opposition – postulated (or at least hypothesised) between these two values or these two norms (that is between autonomy and solidarity) tends to dissolve once we agree to consider that the content of the notion of autonomy is dependent on the cultural context in which it is applied and on its social use, in that the affirmation of the principle of autonomy goes very much hand in hand - as these various situations show - with that of solidarity.

On examination of the concrete practices of individuals and the social, cultural, legal and institutional context within which they are deployed, we clearly cannot assume, as Hooyer K and L.F. Hogle [17] tend to do, that the Western world is uniform throughout and shares the same values. It is clear that the diverse cultural traditions present within the Western world produce an unequal primacy of one value over the other. This does not however preclude the possibility of their coexistence. The reality observed belies any consideration of solidarity and autonomy as two opposing values since it demonstrates not only that the two *do* coexist in French society, but also that this very coexistence proceeds from a redefinition of the contours of the notion of autonomy, that is to say, a widening of its conceptual perimeter.

A necessary condition for the two values to coexist is indeed a reconsideration of the parameters of the notion of autonomy. It seems in fact that we are dealing with a type of autonomy that sits uneasily with individualism, and that includes the collective, even if this endangers individual autonomy. In these conditions, autonomy becomes, not so much the 'right of the *individual* to freely determine the rules to which he/she is subject', as potentially, the right of the *family* to freely determine the rules to which it is subject. Here, the subject's rules are those he/she can put forward when faced with institutions, but this is done as a collective subject. Therefore, this autonomy - to some extent a 'collective autonomy' or a 'family autonomy' - does not imply so much an affirmation of the individual subject, as an affirmation of the family entity faced with an institution, where,

when autonomy is affirmed, it is within a definition that includes solidarity. We have then two non-exclusive values, so that the enactment of the first value may involve the underlying presence of the second.

This phenomenon retains the full political dimension of the notion of autonomy to the extent that autonomy (be it collective or, here, familial) involves freely defining and asserting oneself in the face of authorities or institutions. While there is no antinomy between the two notions, they interweave so closely with each other that the enactment of one redefines the parameters of the other.

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