

Jean Martin*

Veronique Fournier: «Le bazar bioéthique – quand les histoires de vie bouleversent la morale publique»

...Article de recension

...Paris: Robert Laffont, 2009, 213 p., ISBN 9782221115053

Une réflexion française originale et stimulante

Véronique Fournier est cardiologue et médecin de santé publique; elle a été chargée dans le cabinet Kouchner de préparer la loi sur les droits des malades de 2002 et dirige le Centre d'éthique clinique de l'hôpital Cochin, à Paris. «Le bazar bioéthique» présente des enseignements rassemblés au cours des évaluations et recherches menées dans ce centre; traitant des donneurs vivants d'organes (soie surtout), de la recherche de l'enfant parfait (y compris diagnostic pré-implantatoire), de transsexualisme, de situations-limites en matière d'assistance médicale à la procréation (AMP).

Dit ici en toute modestie, je me suis procuré ce livre parce qu'il ne faut pas s'intéresser à ce qui est publié en anglais seulement, m'attendant à un exposé convenu. Surprise bienvenue, dès les premières pages, de découvrir une pensée indépendante, originale, basée sur une pratique substantielle – à la différence d'«experts de salon» parfois éloignés de ce que vivent patient(e)s et professionnels.

Fournier apporte entre autres des éclairages sur les dimensions collectives des enjeux bioéthiques et sur la légitimité ou pas de l'intervention de la forte main de l'Etat. Elle discute le lien, actuellement indiscuté dans la conception française, entre le devoir des pouvoirs publics de mettre à disposition des soins de qualité et le devoir de financer lesdits soins. Demandant si on ne sera pas amené, dans tel ou tel domaine, à séparer les deux choses: à savoir que des prestations puissent être rendues disponibles sans que l'Etat en assume la charge financière – avec les interrogations que suscite alors la survenue d'inégalité dans l'accès à certains soins.

Le consentement éclairé des personnes et sa vérification par des experts – la juste mesure – ou démesure – du contrôle public

La place et l'importance du pouvoir normatif de l'Etat, fixant des interdictions et des droits de regard, sont débattues en bioéthique – il convient parfois de les contester. Quand et jusqu'où faut-il que les pouvoirs publics prévoient le contrôle du bon sens des patients, donneurs d'organes ou couples s'adressant à l'AMP, du caractère raisonnable de leur projets – de vie, ou parentaux, ou de changement de sexe/genre. Des règles sont nécessaires mais on voit aussi des propositions qui donnent l'impression que, forcément, l'Etat sait mieux

* Médecin de santé publique, membre du Comité international de bioéthique de l'UNESCO

que des adultes capables de discernement ce qui est bon pour eux. Au sujet d'un projet de loi censé lever l'interdiction en Suisse du diagnostic préimplantatoire, nous disions «Le lecteur est frappé par une orientation paternaliste: un contrôle serré et pour chaque cas de l'Etat (sage) serait indispensable pour éviter les dérives des couples (irresponsables?) désireux de concevoir» [1].

A propos de donneurs vivants d'organes, Véronique Fournier écrit «il est tout à fait insuffisant, voire parfaitement inadéquat, d'aborder [les situations à examiner] sur un plan [au moyen de critères] purement théorique, à distance de ce qui se vit pour les personnes concernées». L'expérience lui a appris que le raisonnement qui confie à un centre d'éthique l'appréciation du donneur uniquement mais pas celle du receveur est insatisfaisant.

Plus avant: «même si les circonstances familiales étaient telles que l'on pouvait se poser des questions [...], quel contexte familial en est-il exempt et en quoi était-ce notre affaire? N'était-ce pas nous immiscer un peu loin dans la vie des gens? [...] L'expérience m'a conduite à consolider ma méfiance. Il ne me paraît pas opportun d'émettre, ni moi ni du reste quiconque, un avis sur le consentement du donneur». De plus, «La procédure est maintenant devenue si lourde qu'elle en devient presque suspecte» (question qu'on peut poser en Suisse pour la réglementation de la médecine de transplantation). A propos d'AMP: «La conception même d'un garde-fou mis en place par la société pour protéger les enfants des excès de leur parents leur était incompréhensible [aux couples demandeurs]. En revanche, ils comprenaient que leur médecin ait besoin de réfléchir avec d'autres afin de les guider au mieux». Elle cite l'avocat parisien Pierre Verdier, spécialiste du domaine, disant qu'il n'avait jamais vu de parents faire passer leur prétendu intérêt avant celui de l'enfant ...

Au sujet du transsexualisme, elle discute/soupèse les poids respectifs que doivent avoir les souffrances et demandes des personnes concernées, d'une part, et des limites que poserait l'Etat d'autre part. Arrivant à une conclusion qui peut surprendre: «Du reste, peut-être vaut-il mieux que le transsexualisme ne soit pas reconnu comme une question de bioéthique puisque la sanction législative en serait alors probablement restrictive, comme c'est le cas pour tout ce qui relève de la loi de bioéthique jusqu'à présent, tendant à privilégier l'intérêt de la société sur celui de l'individu».

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