Consumer resistance between conflict and cooperation: the extreme case of orphan drugs

Isabelle Chalamon
Centre de Recherche CEREN, Groupe ESC Dijon-Bourgogne, Dijon, France

Abstract

Purpose – This paper aims to explore how consumer groups with limited resources and means of action are able to resist market pressures and how they are sometimes able to modify corporate practices.

Design/methodology/approach – A case study was carried out in France concerning the mobilization of patients suffering from rare diseases. Two data sources are used: semi-structured interviews and documentary sources.

Findings – In this extreme context, the activists fight to expand the reach of existing market institutions so that those who do not have access to a treatment can finally benefit from the existence of a drug. In order to reach this goal, activists need to collaborate with the incumbents so that the system can be reformed from the inside. Resistance then becomes a productive act of power for the targeted firms.

Originality/value – This paper emphasizes a case of minor resistance whose aim is not to radically change the market system but rather to propose moderate adjustments which would allow existing market institutions to extend their reach. It also underlines the cooperative and productive dimensions of certain acts of resistance. Finally, by highlighting a case of pro-consumption resistance, this paper adds to the current debate on the distinction between resistance and anti-consumption.

Keywords Cooperative resistance, Extreme case, Orphan drug, Rare disease, Diseases, Medicines, France

The impact of consumer resistance on corporate strategies is drawing more and more attention and is the subject of a growing body of work (Friedman, 1985; Pruitt and Friedman, 1986; Garrett, 1987; Davidson et al., 1995; Koku et al., 1997; King, 2008). This stream of research is of crucial importance since it raises the issue of the effectiveness of resistance actions. However, these studies are still limited in scope as scholars predominantly focus their attention on one specific form of action: the boycott. Consumer resistance outcomes are therefore mainly understood in one type of political context: that in which the consumers have the ability to develop strong protest actions, which enable them to threaten the performance of targeted-firms. On the other hand, little attention has been paid to the ways in which consumer groups with limited resources and means of action are able to resist market pressures and how they are sometimes able to modify current corporate practices. Studying resistance within extreme political contexts – i.e. situations in which there is a marked inequality and/or a high degree of dependency – would therefore enhance our understanding of how consumer resistance affects firms. In this article, we address this gap by examining...
and documenting an extreme case of resistance: that of patients suffering from rare diseases.

In the European context, a disease is qualified as being a rare disease if it affects less than one person out of 2,000. These diseases are so infrequent that the sales of the drugs developed to treat them could not possibly redeem their research and development costs. Thus, one can speak of “orphan drugs” which implies the absence of “parents” who would be needed to develop the drugs. In the 1980s, patients afflicted with rare diseases, along with their relatives, began to protest against the unfairness of their situation whereby the market imperatives excluded certain illnesses on the basis of their rarity. In this context, the aim of our study is to analyze the strategy used by these activists and its impact on decision-makers of pharmaceutical firms who have little inclination to develop treatments whose profitability is more than uncertain.

This study has several implications for research. First, our work highlights a case of minor resistance whose aim is not to generate a radical change concerning the market system. The goal of this particular form of protest is to propose moderate adjustments that would allow the existing market institutions to expand their reach so that those who did not have access to them can, at last, benefit from what the institutions have to offer. Second, we underline the cooperative and productive dimensions of certain acts of resistance. Finally, our paper adds to the current debate on the distinction between resistance and anti-consumption by differentiating two types of consumer resistance: anti-consumption and pro-consumption actions.

This article is organized as follows: first, a critical review of prior research is presented, followed by a short development on the interest of studying extreme cases. Second, we present the methodology and the research findings. Finally, we conclude with a discussion of these results.

1. Theoretical background
1.1 Consumer resistance impact on targeted-firms
The emerging literature on the consequences of resistance – which until now has approached the question mainly through the study of boycotts – reveals two main areas of interest. One line of research focuses the attention on the identification of the strategic responses of firms to a boycott, in order to measure their effectiveness to limit the protest size and consequences (Brunetti, 2008; Yuksel and Mryteza, 2009). A second stream of research concentrates on the impact of boycott on corporation practices and performance (Pruitt and Friedman, 1986; Garrett, 1987; Davidson et al., 1995; Koku et al., 1997; King, 2008). In this perspective, scholars underline that boycotts can broadly vary in their effectiveness (King, 2008): an empirical examination of corporate concessions to boycotters’ demands found that only a quarter of all publicized actions were successful (Friedman, 1985). Three main factors can explain these differences in terms of outcomes.

First, the mobilization success will depend on how much consumers are able to actually threaten the corporation’s performance (King, 2008; Weber et al., 2009). For instance, some groups used the boycott to effectively curtail sales (Friedman, 1999) or to influence firms’ stock prices (Pruitt and Friedman, 1986; Pruitt et al., 1988). They can also influence their targets by threatening their reputation with media coverage of the events (King, 2008). Thus, economic actors measure the cost of protest and this evaluation influences their decisions to comply. But they also weigh the cost of
conceding to the movement demands, which varies from one organization to another. The characteristics of the target (King, 2008) are therefore a second important set of factors explaining the effectiveness of consumer mobilization.

Certain targets are more vulnerable than others to consumer pressure because they are more fragile. For instance, prior decline in performance, sales revenue or reputation may make firms more vulnerable to boycotts (King, 2008). In addition, a firm may be more inclined to respond favorably to the pressure coming from its market environment. In this context, the “internal life” of an organization can facilitate or inhibit the incorporation and enactment of movement demands (Zald et al., 2005). In particular, employees who share values with movement participants can act as internal advocates and help implement change in the workplace (Weber et al., 2009).

Finally, the context can have a decisive effect on corporate decision-making to comply. Laws and regulations issued by the State can thus evolve to support the movement demand and put pressure on firms (Zald et al., 2005).

This stream of research provides a framework relevant to the understanding of boycott impact on corporate practices. However, by focusing their attention on this anti-consumerist action, scholars have been dealing with only one aspect of the phenomenon. Indeed, if we define resistance as the process by which individuals or groups practice a strategy of appropriation in response to structures of domination (Poster, 1992), this concept includes a larger range of actions and contexts. Protest impact has therefore been studied within one type of political context: that in which the consumers are able to develop strong protest actions which enable them to challenge or even reverse the existing power structure thereby threatening the performance of organizations. Consequently, by focusing the analysis on strong market actors who are able to rely on a large number of resources, we are left with little information concerning the processes by which those whose influence and resources are limited try to change corporations’ practices. In order to expand existing research, we propose to study the impact of consumer protest within a new kind of context – that of extreme cases – which offers numerous advantages.

1.2 Studying consumer resistance in extreme contexts
Several organizational theorists have recently emphasized the importance of studying extreme cases (Stinchcombe, 2005; Clegg et al., 2006; Marti and Mair, 2009). According to Stinchcombe (2005, p. 39), scholars “will find out more by intensive observation of extreme cases because they have more information in them that is not already in the average of the cases […] which is what we need for causal theorizing”. Continuing this line of reasoning, the author suggests that one can learn more about religion by observing “extreme” religion groups which, “generally seem to occupy more of the lives of their members than do mainstream religious groups” (Stinchcombe, 2005, p. 40). The purpose is to see the processes in its “extreme” forms; if we can penetrate the mechanism of one extreme case, we might be able to apply it elsewhere where the analysis is more difficult. Moreover, Clegg et al. (2006, p. 143) emphasizes the importance of “extreme cases” to better understand political phenomenon at work within organizations in order “to see normal phenomena in a condensed and concentrated form”. In this perspective, the authors suggest that the Holocaust, asylums or prisons are ideal contexts to study how power is constructed and how it operates in normal organizations. Thus, extremes cases must be chosen as units of
analysis because the mechanisms of authority and power are far more obvious in those situations.

Following this line of research, we underline the interest of studying consumer resistance in extreme political contexts, i.e. those situations in which there is a marked inequality and/or a high degree of dependency. Indeed, there are many protest groups in a weak position, which have received little attention such as those living in poverty, homeless people or patients waiting for a curative treatment. By shifting the attention towards the analysis of these extreme contexts, we may be able to develop new insights on how activists who have limited means of action successfully resist and even modify corporate practices. With this reasoning, we will focus on one extreme example of resistance: the French mobilization of patients suffering from rare diseases.

2. The case study
2.1 Methodology
This movement can be qualified as extreme for two reasons. First, the urgency and dependency levels experienced by these patients are very high. There are very few treatments available to these patients who are suffering from serious and progressive pathologies. Second, in this context, the end user has very limited possibilities to impact on practices and market rules because of his/her dependency on a delivery system mainly controlled by the pharmaceutical industry.

In order to assess this case, two data sources were used. First, 36 semi-structured interviews were held with French activists, executives of the industry and State representatives who directly participated in key events and decisions. Informants were selected via a snowballing technique following a first meeting with two activists of the l’Alliance Maladies Rares. Each interview lasted from one to two-and-a-half hours. The interviewer encouraged informants to share their visions of the origin of the orphan drug issue, the role played by the movement, and the major changes triggered by the mobilization. Second, two main documentary sources were analyzed in order to add detail to the interviews and to validate the dynamics involved: newspaper data and archival material of two patients’ organizations (the Alliance Maladies Rares and Eurordis, the European Organization for Rare Diseases).

The data collected were analyzed in two phases. First, we developed a narrative account of the events in order to retrace the evolution of the orphan drugs field in France. In the second phase, we systematically coded the information available in three dimensions: the origin of resistance, the goal and the strategy of the resistance movement, and the shape of the interactions between the activists and the industry. Throughout the analysis, the author tacked back and forward between literature and data, in order to interrogate and refine these themes. In the next section, the results of this analysis are presented and illustrated by quotations taken from the interviews.

2.2 Results
The orphan drugs issue was brought to light in France in the 1990s, following an Inserm[1] report done by Annie Wolf on “The Orphans of Health”. To continue this work, the Minister of Social Affairs Simone Veil created a Mission for Orphan Drugs in 1995 and appointed Annie Wolf as director of the project. Aware of the need to make the patients more aware of the issues involved, Annie Wolf was also conscious that the large number of already existing patient associations had to be organized into one

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single federation, as the existing organizations were divided and structured by diseases (see Figure 1).

In September 1996, a national symposium on this issue was organized in the Senate. The patients thus being gathered understood that, beyond the particularities involved in their various diseases, they had a common factor which could lead them to become federated: the scarceness and absence of treatment. From this awareness, a resistance movement emerged in order to fight against this unjust situation.

I'm part of those people who resisted... the ignorance which surrounded rare diseases, the indifference and the inertia (Active member of the Alliance). The starting point was the family members of the patients who realized that in the existing system there was no way out, no hope to have any medication developed [...] the market was in no way promising... and since that industry is not a philanthropic one, it wasn’t doing anything (Director of the Orphan Drugs Mission).

Having understood that the industry had no interest in developing medications for such a small segment of the population, the patients and their relatives decided to publicly demonstrate their opposition to a market system which excluded patients affected by rare diseases and strongly voiced the necessity for change in practices.

At first, the protesters acted against pharmaceutical companies by using assertive opposition, thinking that they could thereby influence the firm’s decision-makers who would have become aware of the importance of the issue involved.

In the beginning, when I spoke out in public, I was into confronting others, I had an ‘in your face’ attitude [...] so, we were into confrontation to start out with (Active member of the Alliance).

However, they soon had to face the fact that direct opposition was not an effective protest strategy because of the asymmetrical relations existing between the patients and the industry, as well as the dependant situation of the patients themselves.

The pharmaceutical industry controls everything, you can’t ignore that, you can protest as much as you can, or suck up to them as much as you like, but you can’t simply tell them to piss off (Active member of Eurodis).

Being in an unbalanced position, the patients had little means to radically change the market imperatives and the decision-making process it triggers. Besides, the activists were aware that they needed the firms since the pharmaceutical companies are the only

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**Figure 1.** Cumulative number of patients organizations in the field of rare diseases in France

**Source:** The “Annuaire Tricot des associations”
economic actors who have the resources and the necessary skills to develop and market
the drugs essential to their survival. Their goal therefore quickly changed, to become
more subtle, more nuanced. Aware of being in a weak position, protestors decided to
try to extend the reach of the existing market institutions so that those who did not
have access to a treatment could finally benefit from the existence of these drugs. For
this purpose, they understood that they had to work alongside the dominant actors –
the industry’s – and take into account their interests in order to improve the system
from the inside.

To set up a constructive dialogue, activists decided no longer to fight the market
system but rather to accept it, as seen in the testimony of this activist who seems fully
aware of the need to integrate the rationale of the industry – especially taking into
account the profit factor – in order for this to work for the cause:

If you go to a gas station and say 'fill it up at half price' simply because you need gas, they
won’t do it. The patients have the same demands but they are stated more realistically […]
Why would anyone develop medication to lose money, like why would anyone make bikes if
they were losing money? There is no utopian rule which would enable the pharmaceutical
industry to escape the economic system (Active member of Eurodis).

In order to find a solution, it was also essential not to consider the pharmaceutical
companies as the problem but as the solution and therefore to act with them and not
against them.

It is not a question of throwing ourselves against the industry; it’s seeing how to make things
change together (Active member of Eurodis).

The protest then evolved from a strategy of opposition to a strategy of cooperation,
without being co-opted, however. Each party had to defend its position and deal with a
confrontation of ideas.

What counts is that the roles stay clear and that a patients’ organization won’t lose its soul. It
is not there to defend the needs of the industry; it is there to defend the needs of the patients
(An industry executive).

From this dialogue, the activists understood that an adjustment of the market
institutions was necessary to reduce the financial risks involved and to improve the
potential return on sales of these treatments. It became therefore necessary to fight for
the introduction of a new European regulation whose aim was to transform the
marketing conditions of the treatments concerned.

Aware of the need to federate the movement at the European level to support the
project, the French activists acted to create a collective of European organizations –
Eurodis – set up in 1997. More than 200 associations coming from 14 European
countries quickly came into the new organization. The Alliance Maladies Rares was
then created to federate the French associations and to integrate the coalition. Under
the drive of this mobilization, a European regulation was voted in December 1999. Its
goal was to financially stimulate firms to develop these types of drugs, by giving them
exclusive rights on the market for ten years, as well as tax cuts and funding. By
allowing development costs to be covered more easily, this regulation rapidly
encouraged a growing number of pharmaceutical firms to invest in these niche
markets, which had been neglected up to then (see Figure 2 and Table I).
3. Discussion

Several aspects of our case study can be discussed in order to confirm the interest of extreme cases for generating new theoretical developments.

First, we observe a strong will to resist in the patients and their family members. They openly demand the necessity for change so that they may break out of the dead end situation of having no medical treatment available. On the other hand, their purpose is not to radically question the decision-making process of pharmaceutical firms nor even the capitalist system in which they are evolving. Their priority remains
relatively modest, and is limited to a demand for market adjustment, which would no longer exclude them from the market and yet respect specific market constraints such as the principle of profitability. Consequently, by removing ourselves from the context of traditional studies, we can observe that resistance projects are not always based on the will for a radical change. These kinds of actions – that could be qualified as minor acts of resistance – are consistent with the ideas of “enhancing work” (Martí and Mair, 2009) or “enabling work” (Lawrence and Suddaby, 2006) developed by institutional theorists and defined as those actions that create rules which facilitate, supplement or support existing institutions. These forms of resistance require the development of collaboration strategies with the incumbents so that the system can be reformed from the inside. Our study therefore highlights the cooperative dimension of certain forms of resistance, which has hardly been addressed by other studies.

The activists in this case put themselves in a position of acceptance of the decision-making rules and propose to cooperate with the dominant actors in order to find a creative solution to their joint problem. They find themselves in a paradoxical situation of resistance/cooperation, which is relatively difficult to explain with the current definition of consumer resistance. Indeed, this concept is too often thought of as synonymous with direct opposition to corporations and disobedience to market rules. Scholars have thus a tendency to overestimate the contentious dimension of resistance and, consequently, to neglect its cooperative side. A more nuanced vision of resistance is therefore required in order to include the diversity of forms resistance can take. Moreover, by underlining that protest and cooperation are not necessarily antithetical, this study furthers the discussion whereby resistance actions can become productive for the targeted-firms.

The wills of consumers and producers are indeed far more overlapping, mutual and interdependent than commonly recognized (Kozinets et al., 2004). By allowing new strategic options to be discovered, protestors can become a source of opportunities for firms. Consequently, speaking of “productive” resistance (Courpasson and Golsorkhi, 2009) means highlighting the strategic advantage activists can bring to organizations. By thinking of resistance as the expression of counter-proposals, it can become a constructive act of power and the ability to resist – i.e. the ability to invent alternative and credible ways of operating – also participates in organizations’ adaptation and modernization (Courpasson and Golsorkhi, 2009).

In addition, by examining a case of resistance that is not based on anti-consumption behaviors, this paper adds to the current debate on the distinction between these two concepts. As noted earlier, focusing on resistance means to investigate the strategies of appropriation practiced by individuals or groups in response to structures of domination (Poster, 1992). Resistance is therefore a state of opposition to a force, which is perceived as being oppressive and unacceptable by the consumer. In this perspective, our case study helps to make the distinction between two kinds of resistance situations. First, market structures can be perceived as oppressive by consumers who feel they are victims of consumer culture, and marketing messages that seem to take control of their desires and preferences. In this context, the consumers will generally show their opposition by anti-consumption behaviors, in order to get back some degree of autonomy in their decision-making. Second, the market rules can exclude certain populations because of the lack of potential financial gain. In this second context, the resistance will be led by actors who are excluded from the marketplace and whose aim will be to have access to consumption, thus taking the extreme case of orphan drugs.
form of a pro-consumption activism. Consequently, resistance must be considered as a state of opposition which could lead to varied consumer responses and which are not limited to anti-consumption. In addition, anti-consumption behaviors can be considered as forms of action enabling consumers to resist a specific type of pressure coming from the marketplace.

Several implications concerning both drug manufacturers and policymakers can be made from this study. First, this research underlines a major evolution in the health sector: that of the new role-played by the patient. Over the last 20 years, patients have shown a form of resistance to medical discourse and more openly express their demands concerning the inadequacies of the health care system. Our case emphasizes the fact that these acts of resistance are in some measure acting on the evolution of the health care system in a positive way, not only by publicly recognizing health problems which have been ignored but also by finding new solutions to unresolved problems or deficiencies in the health care system. This work stresses the importance of a growing need to integrate patients into the decision-making which concerns them, in order to make the health care system more efficient, fairer, and more in touch with the needs of our society.

Second, this study demonstrates that it is in the interest of the industry itself to pursue the development of orphan drugs for two main reasons. First, orphan drugs development opens the possibility of having a major impact in innovation in so far as most of the treatments developed in this field lay the grounds for major therapeutic progress in general. Second, these types of drugs will allow laboratories to position themselves as pioneers in the development of targeted therapies, which is presented by many experts as being one of the most promising sectors of the industry. However, in order to incite companies to invest more in this domain, an international harmonization of market authorization procedures must be considered so that laboratories will be able to offer these treatments to a larger number of patients more quickly. The differences in the existing regulations causes the profitability of these treatments to remain uncertain, thereby making laboratories hesitant to invest in these market segments which have real market potential. Moreover, many diseases remain “orphans” (as they have no treatments available) because of a lack of knowledge concerning their evolution. Policymakers must therefore keep in mind the importance of investing in fundamental research so that laboratories will be strongly encouraged to focus on market segments which have been ignored until now.

Note

1. The French National Institute for Health and Medical Research (Inserm) is a public scientific organization, overseen by the French Ministries of Research and Health.

References


Corresponding author
Isabelle Chalamon can be contacted at: isabelle_chalamon@hotmail.com

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