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A lay prescription for tailor-made drugs—focus group reflections on pharmacogenomics

Anna Birna Almarsdóttir[a,*], Ingunn Björnsdóttir[b], Janine Morgall Traulsen[c]

[a] *Faculty of Pharmacy, University of Iceland, Hagi, Hofsvallagata 53, IS-107 Reykjavík, Iceland*
[b] *The Pharmaceutical Society of Iceland, Box 252, IS-172 Seltjarnarnes, Iceland*
[c] *Department of Social Pharmacy, Pharmaceutical University of Denmark, Universitetsparken 2, DK-2100 Copenhagen Ø, Denmark*

Abstract

This study explores the lay view of pharmaceutical research and development—specifically pharmacogenomics. Forty-two persons participated in eight focus groups in Iceland. Participants were asked to comment on a future scenario consisting of predictions made by researchers concerning the consequences of the Human Genome Project over the next 40 years, and asked to give advice to politicians and the pharmaceutical industry. A dominating theme in the focus groups was the expectation that drugs developed based on pharmacogenomics will be more expensive than conventional mass produced drugs and concerns were voiced that this new technology would lead to inequalities locally and globally.

Keywords: Pharmacogenomics; Lay perspectives; Pharmaceutical R&D; Genetics; Focus groups; Iceland

1. Introduction

1.1. Pharmacogenomics—societal and industry implications

Pharmacogenomics has been widely discussed in the scientific literature and talked about by medical journalists as "... taking industry by storm" [1]. The concept has been defined as the study of the interaction between a drug and any gene, or multiple sites throughout the genome [2,3]. Recently, medical news reported that US FDA is seeking genome-based drug data and reviewed three scenarios where pharmacogenomic information would be used in regulatory decision making regarding drugs [4]. The first scenario was about a drug that has already been approved where the company that developed it could try to identify the patients most negatively affected to fine-tune the drug and make it safer. The second scenario addresses drugs found to be metabolised differently by different individuals where doses could be adjusted accordingly. The third scenario envisions the development of a drug tailored for patients with a specific genetic profile. This could mean a huge clinical benefit to patients; however, a debate of the economic implications for society and the pharmaceutical industry has recently begun to surface [1,5–8].

* Corresponding author. Tel.: +354 525 5217; fax: +354 525 7041.
E-mail address: annaba@hi.is (A.B. Almarsdóttir).

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The implications of pharmacogenomics for industry have been described by one of the leaders in the field of genetics, Dr. Allen Roses, as a disruptive technology that will upset the way organizations are run today [1]. Thus pharmacogenomics is seen to be one of the largest change agents in health care. The first implication of this technology is that patients will be routinely genetically tested in order to narrow their drug treatment choices. The second is that it will involve a new approach to drug development making the process shorter and more efficient. This in turn leads to a segmentation of the market for each drug based on genomic indicators. Pharmacogenomics runs counter to almost every conventional notion of how drugs are developed and marketed today. The large pharmaceutical companies rely on blockbuster drugs to secure their viability and are threatened by a fragmentation of their market. Some industry spokesmen have countered this fear of pharmacogenomics by stating that developing safer drugs will pay off for the industry and provide huge competitive advantage. As stated by Allen Roses of Glaxo Smith Kline:

"Would you pay more for a pill that is a thousand times safer?" [1]

This is indeed an interesting question with implications for health policy. Is there a willingness to pay for this new technology? Enormous resources are used to determine prices and reimbursement rates of drugs. Health care managers are concerned about rising costs of drugs and economics research has been carried out to determine the reason underlying this development. A recent study found that new drugs account for about one-third of the rise in drug budgets in the United States [9]. The other main reasons are price increases of already marketed drugs and increased drug utilisation (about one-third each).

It is important to be aware that previously, the driving forces behind the adoption of new drugs were prescribers, but both the mass media and the lay public are increasingly becoming active players.

1.2. Lay views and involvement

Although we see an increase in research focused on lay attitudes towards genetic screening, research on public involvement in policy decisions regarding genetics is scarce. One study in the US focused on membership in federal advisory committees evaluating public policy in genetics [10]. The results of this study showed low involvement by lay persons who were either defined as consumers of technology or people without expertise in the field of genetics. The authors conclude that there exists ample room for greater public participation in federal advisory committees on human and medical genetics. Issues of informed consent, privacy, and discrimination are predicted to be important as sophisticated genetic diagnostics make their way into practice [11].

Studies have shown that various patient and population groups respond to and interpret the impact of genetics on their health and lives differently [12]. In the pharmaceutical arena a few well-publicised cases have shown the importance of listening to the lay voice. Suffice it to review the impact AIDS activists have had on the legislative environment and pace of research into pharmaceuticals. This points to a new direction of sociological research on genetics where the importance of the public's view is increasing.

Recently, results of focus groups related to pharmacogenomics were published [13,14]. The objectives of these focus groups were to understand public perceptions and attitudes towards pharmacogenomics based on individuals and race. Both studies were conducted in urban, suburban, and rural Georgia (in the South Eastern U.S.) oversampled for minority groups. These studies were so called "reactance format focus groups" where participants received basic information about the phenomenon being discussed (in this case pharmacogenomics) at the start of the focus group and provided responses in light of that information.

Bevan et al. [13] found that focus group members identified individualized genetic testing as providing the best quality of care, but stipulated the need for protection from the invasion of privacy, discrimination, and prohibitive costs. Most individuals chose genetic testing because it provided individualized attention. The results reported indicate that the focus groups are suspicious of race-based prescribing.

This article explores the perspective of laymen in Iceland who have been heavily exposed to media reports and debates on genetic research. We pose the question of whether there is a demand from the end-user for the products of pharmacogenomics and can we anticipate it?