FROM BLIND TRUST TO Crippling Fear - One Consumer’s Perspective
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These are some of my thoughts about medication, medication incidents and the role we consumers play. I have my own biases because I am not a “naive” consumer, but was involved in pharmacology, health research, and in health system administration before I retired. I am now a consumer without any personal connection to the health system. It is my impression that consumers of health services (patients, clients) are not seen as central to the huge health care industry; this is almost too ludicrous to write, for without consumers we would not need the system.

Canadians consume many medications, so safe medication use is very important to us. We know, theoretically, that medications offer us and our families many benefits. We know they may: improve our quality of life; improve our length of life; improve our ability to function; make us feel better, or slow down some decline; and, prevent future illness or disease. We know that highly trained health professionals have the responsibility to prescribe, dispense, and often administer medications that they believe offer us benefit.

We also know that the pharmaceutical industry is very large and is an economic driver of great significance. We suspect the balance between their altruistic purpose and their business interests may not always be in favour of the consumer (unless the consumer is a shareholder). We know they apply pressure on governments and health professionals to put products on the market quickly, often with tragic consequences.

We do not know much about risks related to medication use, nor do we have easy access to information about the risks that others have been exposed to. We also do not always have confidence that those who prescribe or dispense medications know much about the risks involved either. We know there is a lack of information about risks and about errors that have occurred. If this type of information was collected and discussed openly, we believe better decisions about medication use would occur.

Consumers obviously play an important role in this discussion because we are the “users.” Amazingly, we are not very involved in the process, except to be the recipient of the medication. We are expected to trust others (i.e., health professional -- physician, pharmacist, or nurse) about risks, benefits, costs, doses, adverse effects, interactions. I believe health professionals would greatly improve their knowledge by listening to patients about the impact medications have, beyond those signs seen by laboratory or other diagnostic testing. We must not allow ourselves to feel bullied into taking medication without understanding consequences. Whenever feasible, we must take time to understand the medication’s purpose and what alternatives may exist. Health professionals must make time to answer questions, allay concerns, and direct us to more information if that is what we need.

Consumers are bombarded with a plethora of mixed messages about medication use. Media sensationalize incidents out of context. The pharmaceutical industry promotes
brand-specific products without balancing risks and benefits. Governments allow medications to be marketed without demanding systems for monitoring or surveillance. Health professionals seem too busy to engage patients in full dialogue about treatment alternatives. So consumers are left to sort through the messages in whatever way they can. Fear and distrust are often the consequence.

When medication errors occur, they happen to us, not to the media, government, or industry! We have to be involved in any process created to help prevent medication errors. I believe consumers are willing to ask questions, tell health professionals about experiences, report problems/incidents, be actively involved in their own and their family’s health, and follow instructions about medications. I believe we expect balanced reporting from media and the health system, and will continue to lobby for impartial sources of drug information -- not just blind faith in a single health professional. We also have the responsibility to fully disclose medication use and alternative therapies, accept risks, get help if costs influence choices about medication use, and demand full disclosure from government, from the pharmaceutical industry, and from the health system.

I believe that Canadians want to be involved in making the current system better. Improved communication among us is essential. It is hoped that the work of the Coalition of Medication Incident Reporting and Prevention supported and chaired by Health Canada will start making a small step in the right direction.

Linda Strand Ph. D is a consumer of health care and is also a member of the Canadian Coalition of Medication Incident Reporting and Prevention, an initiative supported by Health Canada.