

Communicating Risks Associated with Psychiatric Drugs
To the Public

E Daisy Anderson
For
Psychiatric Medication Awareness Group

Presented to

Health Canada Expert Advisory Committee on the Vigilance of Health Products
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Chair, Committee members:

My name is Daisy Anderson and I am presenting on behalf of the Psychiatric Medication Awareness Group, or PMAG.

Communicating Risks Associated with Psychiatric Drugs to the Public:

Our information and recommendations are based on research and what we have learned from those impacted by psychiatric drugs. Many of the issues surrounding psychotropics may also apply to other medications.

Our non-profit organization is a group of dedicated volunteers providing information about the safe use of psychiatric drugs. PMAG is one of the few non-industry-funded resources working in this area in North America.

We sponsored Dr. Heather Ashton, world expert on benzodiazepines, to give seminars to 400 health professionals, especially on how to safely get off.

We produced the booklet: "What People Need to Know About Psychiatric Drugs." Hundreds of copies have been distributed across Canada. A new edition will be available in 2009.

Of special interest on our web site is the video of Dr. Ashton's presentation. It has been viewed by 32,000 people in 1½ years.

In our work of risk communications, we see a hunger for the full story about the risks associated with psychiatric drugs, especially how to get off safely.

Risk Communications Must Target All Canadians:

Estimated that adverse medication reactions kill 1800 Canadians a year. Canadians would not tolerate 12 airplanes crashing out of the sky, each time killing 150 people. So, why put up with so many deaths from adverse reactions? That is why this consultation is so important.

We, the public take psychiatric medications and we are the ones who experience chronic illnesses, disability and even die as result. Over prescribing of psychotropics is a hidden public health crisis.

1. Fall-related injuries in Canada among those 65 and older have been estimated to cost the economy \$2.8 billion a year. Benzodiazepines, anti-psychotics, and the older and newer antidepressants all increase the risks of falling.

2. The Federal Drug Administration in the USA has warned of increased risk from suicide by 33 different antidepressants, including SSRIs.
3. Akathisia is an effect of anti-psychotics and antidepressants. Patients describe this effect like "the sensations of nails scratching the blackboard, 24-7."
4. Estimated that 50% of those taking an anti-psychotic will eventually experience tardive dyskinesia. TD is painful, disfiguring, potentially life threatening and often permanent. SSRIs also cause TD.
5. We have a type II diabetes epidemic in Canada. It is unjustifiable that we are adding to this by the over prescribing of metabolic disrupting medications, the anti-psychotics.
6. Public Safety Issue:
 - July of this year, the federal government's "Tackling Violent Crime Act" gives police the ability to investigate and charge drivers impaired by prescription medications. Most people are not aware that if they take a sleeping pill at 11 or 12 o'clock at night then drives at 8 the next morning, they can be impaired.
 - In the year 2002, in BC, over 10,000 people received more than enough benzodiazepine tablets to possibly be chronically impaired and thus not able to drive or work safely or care for children adequately.
 - With our current economic downturn, people may resort to antidepressants or sleeping pills. The possible sedative and cognitive effects could actually go against them. Especially during tough times, people need their wits.

Risk Communications Must Target Vulnerable Populations:

1. Between years, 1993-2002 there was a five-fold increase in anti-psychotics prescribed to children.
2. In 2007, the Globe and Mail reported that close to one-half of the child-wards in Ontario were taking psychiatric drugs.
3. The American Geriatrics Society reported that anti-psychotics were prescribed to 24% of nursing home residents within one year of their admission. Almost 10% of those received an initial dose exceeding the recommendations.

4. In year 2000, one in three status Aboriginal women over the age of 40 in western Canada were prescribed the highly addicting benzodiazepines.
5. The highest number of benzodiazepine prescriptions in BC, year 2002 went to women and the elderly; the two groups most vulnerable to their adverse effects, including falls and hip fractures.
6. Closely associating those living without a home with mental illness increases the chance they will be prescribed psychotropics. This in spite of many having street drug issues.

Consequences of Not Communicating Risks:

1. My story is an example of the high costs of unemployment and disability. I was labeled mentally ill with medication as the mainstay of treatment. Over a 35-year period, the government spent \$1,000,000 that kept me sick. This is 10 times more than what it cost to become well. I have taken no pills, seen no psychiatrists for over 6 years. It is unconscionable to expect citizens who are given psychiatric diagnoses to live suspended in chronic illness.
2. These costs began with a low dose anti-psychotic to help with sleep. Within six months I was on four different drugs and unable to work. Adding drug to treat drug effects is called cascade prescribing.
3. A friend was prescribed lithium and for 35 years the doctors watched her kidneys fail. Each time they tried to stop the drug, she became agitated which they believed was her manic illness. Then she required a nephrectomy for cancer and was taken off all her medications appropriately. She is managing well. Including having gone through a prolonged family situation with no mania, no depression and no pills. She is now facing the possibility of dialysis and is one of our dedicated salespersons for the booklet.

Medication Literacy is Fundamental for Risk Communications

What Do People Know about Their Medications?

From what I see in my work: not much.

People tell me they know they should ask questions, but do not know what to ask. Others see asking questions as challenging their trusted doctor. When people ask and keep asking questions their health care providers become more attentive and the professional relationship more productive.

PMAG recommendation one: determine what people know about their drug, how they learned it and its accuracy as a baseline for evaluation of all risk communication activities.

Three Examples of Barriers to Medication Literacy:

1. Extreme fatigue and blurred thinking.
2. Pressure to accept medication as the solution for a quick return to normal life.
3. Of particular concern in psychiatry, is coercion. Some people are not given a fair opportunity to learn and ask questions.

When barriers are present, some people passively accept medication because they are less able to advocate for themselves.

PMAG recommendation two: determine the barriers to acquiring knowledge about medications and ways to overcome them.

On the other side, people with good knowledge may be deemed not credible because of their diagnosis. One mental health worker said, "Patients were always telling me these drugs are addicting."

PMAG recommendation three: distribute basic medication information such as the booklet, "What People Need to Know about Psychiatric Drugs." This book was written to address basic drug knowledge and how to ask questions.

PMAG recommendation four: tap into the vast store of risk information, that is largely ignored: the experiences of those impacted by the effects of psychotropics. Encourage advocacy. When people are directly and equally involved in their health, they do better.

What is Fair "Risk Communications?"

Fair communication must be honest, complete and up-to-date. This includes leaflet information in pill packages.

It is:

- Unfair not to mention possible drug-effects because "not enough is known."
- Misleading to downplay "addiction" by calling it a "discontinuation syndrome."
- Unfair to not list a serious effect because it might scare people, then abdicate responsibility with: "If you have any concerns, contact your doctor"

People need to know what to look for and what to do if there is problem.

Fair communications includes offering options and ensuring they are readily available, especially as -

Fifty and upwards to 90% of those hospitalized with mental disease may have had adverse life experiences. One large study shows that early psychotherapy, not SSRI can prevent chronic PTSD.

PMAG recommendation five: develop guidelines for ethical and responsible information for risk communications to the public.

PMAG recommendation six: Health Canada work with provincial governments, physician groups, consumer organizations and other professionals to ensure evidence based non-drug therapies for mental disease are readily available. And ensure that non-profit groups have sustainable funding for programs that complement formal treatment and offer alternatives.

Quality Information for Risk Communications

In June of this year, The BCMA stated that "There is no common, independent source of drug information readily available for patients and physicians to make informed decisions."

PMAG recommendation seven: create a centralized clearing-house of information for physicians and the public.

PMAG recommendation eight: Health Canada collaborate with physician groups to prepare guidelines for all classes of psychotropics, then institute educational programs and finally monitor prescribing practices.

Effective Ways to Communicate Risks:

PMAG gave a 2½-hour seminar on benzodiazepines to 175 people and distributed large quantities of literature. All for free. This effective approach was in response to three non-profit societies responding to a need. The turn out is a good example of the public's hunger for information.

The second Opinion Society in Whitehorse, is a consumer organized and run group that provides balanced information about psychiatric drugs. They advocate that consumers make their own choices and that a variety of options are available.

PMAG recommendation nine: Health Canada provide funding for community non-profit groups that receive no industry money, who thus, have no conflict of interest, to develop creative projects to communicate risks and evaluate results

Risk Communications Must Include Addiction to Psychiatric Drugs:

The potential of addiction for all psychiatric drugs and how to help people get off safely is a serious information gap. Accidentally addicted people become angry. This sensitive area must be addressed with humility, competence and compassion.

Yet, there are no dedicated programs in Canada for these people and they tend to seek help from many resources. Risk Communications must go to non-medical professionals and community non-profit organizations.

PMAG recommendation ten: Promote physician education on addiction to psychiatric medications, including safe and effective tapering protocol.

Develop education and support programs for those wishing to get off their medications. Recognize that the needs of those accidentally addicted by the medical system are different than for other addictions. Thus, for services to be effective, they must be separate.

Reporting Adverse Reactions is one positive outcome of risk Communications

People act when they see a need. Several reasons people do not report:

- "Oh, the doctor will do that."
- Some do not make the link between their drug and their illness, i.e. embolisms, weight gain that seems impossible to control, fatigue, muscle weakness.
- Do not make the connection between a drug they were on years ago and their current health issue. Cancer, for one.

PMAG recommendation eleven: All risk communications include: Why, how and what to report.

Communicating risks associated with psychiatric drugs is a crucial first step to ensuring that people have the knowledge to make informed decisions and the drugs are used in a safe manner. Thank you to Health Canada and this committee for allowing the Psychiatric Medication Awareness Group to offer our insights and we look forward to seeing the outcomes of this consultation.