Presentation of benefits and harms of antidepressants on websites: A cross-sectional study

Maryanne Demasi^a and Peter C. Gøtzsche^{b,*}

Abstract.

BACKGROUND: Many people use the Internet for obtaining information about their medications.

OBJECTIVE: To investigate whether information about antidepressants on popular websites reflects the scientific evidence and enables people to make informed choices.

METHODS: Cross-sectional study using a checklist with 14 predefined criteria of 39 websites from 10 countries.

RESULTS: All 39 websites mentioned the benefits of antidepressants. Twenty-nine (74%) websites attributed depression to a "chemical imbalance" or claimed they could fix an imbalance. Sexual dysfunction was mentioned as a harmful effect on 23 (59%) websites while five (13%) mentioned emotional numbing. Twenty-five (64%) stated that antidepressants may cause increased suicidal ideation, but 23 (92%) of them contained incorrect information, and only two (5%) websites noted that the suicide risk is increased in people of all ages. Twenty-eight websites (72%) warned patients about withdrawal effects but only one stated that antidepressants can be addictive.

CONCLUSIONS: None of the websites met our predefined criteria. The information was generally inaccurate and unhelpful and has potential to lead to inappropriate use and overuse of antidepressants and reduce the likelihood that people will seek better options for depression like psychotherapy.

Keywords: Antidepressants, harms, benefits, depression, websites, misinformation

1. Introduction

The Internet is an important source of information about diseases and treatments. It is used by most people [1,2] and often influences their choices and perceptions about medications [3,4]. It is therefore essential that the scientific information on websites is accurate and balanced.

News stories often contain inadequate or incomplete information about the benefits, harms and costs of drugs [5]. These stories are sometimes influenced by information from websites, which may be prejudiced by industry funding and act as direct, or as a proxy, for direct-to-consumer advertising increasing drug sales [6]. When psychotropic drugs are involved, this might reduce acceptability of psychotherapy [7].

^aNordic Cochrane Centre, Copenhagen, Denmark

^bInstitute for Scientific Freedom, Copenhagen, Denmark

^{*}Address for correspondence: Peter C. Gøtzsche, Institute for Scientific Freedom, Copenhagen, Denmark. E-mail: pcg@scientificfreedom.dk.

Antidepressant drugs like selective serotonin reuptake inhibitors (SSRIs) are standard treatment for depression although there is a vigorous debate about their clinical value, which has led to public confusion about the true benefits and harms of these medications [8].

It is a prerequisite for informed consent, according to Canadian and Australian Codes of Conduct standards [9–11], that people are offered information in a manner that helps them understand the problem and the available treatment options. This information must include the known harms "when an adverse outcome is common even though the detriment is slight, or when an adverse outcome is severe even though its occurrence is rare," like suicide and other deaths [9–11].

In August 2018, we searched PubMed with "websites AND antidepressants" and found 44 articles, none of which were studies examining the claims made about antidepressants on public websites. To determine whether people are offered reliable information about the benefits and harms of antidepressants enabling them to make an informed decision, we reviewed the most popular websites in ten countries.

2. Methods

2.1. Selection of websites

We tried to mimic what most people would do when searching for information on the Internet and therefore chose easily accessible websites, which appeared at the top of a Google search. We searched the term *depression* and when this did not provide information about pharmacological therapy, we searched the terms *antidepressants* or *depression therapy*. Due to language restrictions, we chose ten countries where English or a Nordic language is spoken: Australia, Canada, Denmark, Ireland, New Zealand, Norway, South Africa, Sweden, UK, and USA. We avoided websites that were clearly aimed only at health practitioners or that required logins. Each webpage was archived and dated; the time frame was April to August 2018. We reviewed at least two websites per country (see list of the websites in Supplement S1). Doubts about inclusion were resolved by discussion between the authors.

2.2. Data extraction

One researcher focused on the websites in English, the other on those in Nordic languages. Doubts about data extraction and their interpretation were resolved by discussion. We classified the websites into three groups, primarily based on the information provided in the "About us" section, according to whether they were governmental institutions, advocacy groups, or consumer organisations. We determined that the purpose of advocacy groups was to promote the interests of patients and families, whereas consumer organisations generally provided information about healthcare services that are offered to patients and citizens (Table 1).

When information about funding was unclear, we emailed or phoned the organisations. Judgments about whether the websites met the standards for informed consent were based on the guidelines by the Medical Board of Australia [9], Australia's National Health and Medical Research Council, (NHMRC) [10] and the Canadian Medical Protective Association's Good Practices Guide [11] (see Table 2).

Based on a list of 14 predefined criteria, we assessed whether the information presented was trustworthy, given the available evidence (see Table 3) [12–40]. These criteria were either of obvious importance considering the research literature on antidepressants, or represented controversial issues, e.g. whether the drugs are safe during pregnancy, which is also important to know for the users.

Country	Government $n = 9$	•	Consumer $n = 15$	Total $n = 39$
Australia		5	2	7
Canada	2		1	3
Denmark	1		1	2
Ireland	1	2		3
New Zealand		3	3	6
Norway	1		1	2
South Africa		1	1	2
Sweden	1	1		2
United Kingdom	1	3	1	5
United States	2		5	7

Table 1
Types of websites from ten countries

2.3. Patient and public involvement

We did not involve patients or the public in our research project. One of us (PCG) communicates very often with patients, relatives and the public about psychiatric drugs and is Protector for the Hearing Voices Network in Denmark.

3. Results

We included 39 websites [w1-39] (see Supplement S1), 9 from governmental institutions, 15 from advocacy, and 15 from consumer organisations (see Table 1). Twenty-one (54%) of the websites were not funded by the drug industry, 12 (31%) received industry funding and the remaining six (15%) did not respond to our requests for clarification.

None of the websites met our predefined standards for scientific evidence (see Table 4).

3.1. Effectiveness of antidepressants

All 39 websites mentioned the uses and benefits of antidepressants. For example, an Australian website claimed, "most people (60–70%) will recover in 6 to 8 weeks of taking antidepressants" [w30]. Another Australian website stated that, "around 70% of people with major depression start to feel better with the first type of antidepressant they are prescribed" [w29].

Others took a more measured approach stating that, "a significant percentage of people may not respond to a prescribed antidepressant" [w20] or that, "For some people with mild depression, antidepressants seem to have little effect. However, for people with more severe depression, antidepressants often make a big difference" [w21].

3.2. Relapse of depression and duration of treatment

Twenty-two websites (56%) claimed that antidepressants could prevent relapse, advising that medications should be taken typically for six to nine months, and some websites even suggested for a lifetime. For

Table 2
Canadian and Australian standards for informed consent

Guideline	What is informed consent?
Canadian Medical Protective Association; Good Practices Guide	The physician is required to provide information that the "reasonable" patient would want or need to make a decision. Elements of informed consent are: Diagnosis Proposed treatment Chances of success Risks (material and special) Alternative treatments Consequences of no treatment Answers to questions
Medical Board of Australia	Informed consent is a person's voluntary decision about medical care that is made with knowledge and understanding of the benefits and risks involved. The information that doctors need to give to patients is detailed in guidelines issued by the National Health and Medical Research Council (NHMRC).
	Providing information to patients in a way that they can understand before asking for their consent.
National Health & Medical Research Council, Australia	The community recognises that patients are entitled to make their own decisions. In order to do so, they must have enough information about their condition, investigation options, treatment options, benefits, possible adverse effects of investigations or treatment, and the likely result if treatment is not undertaken.
	The guidelines are based on the general principle that patients are entitled to make their own decisions about medical treatments or procedures and should be given adequate information on which to base those decisions.
	Information should be provided in a form and manner which help patients understand the problem and treatment options available, and which are appropriate to the patient's circumstances, personality, expectations, fears, beliefs, values and cultural background.
	Patients should be encouraged to make their own decisions.
	Normally discuss the degree of uncertainty of the therapeutic outcome and the consequences of not choosing the proposed treatment.
	Doctors should give information about the risks of any intervention, especially those that are likely to influence the patient's decisions. Known risks should be disclosed when an adverse outcome is common even though the detriment is slight, or when an adverse outcome is severe even though its occurrence is rare. Influenced by the likelihood of harm and the degree of possible harm more information is required the greater the risk of harm and the more serious it is likely to be.

example, a Swedish website stated that, "after you are healthy from your depression, you need to continue your treatment for a period of time. In some cases, antidepressants must be taken life-long" [w38]. A Norwegian website stated that, "if you have previously had recurrent depression, recommendations may be continuous drug treatment" [w36]. However, to our knowledge, no scientific studies have been conducted to support the need to take antidepressants for a lifetime [17–19].

Table 3
Predefined criteria

	Criteria	Standards for scientific evidence
1	Effect	Effect estimated in meta-analyses of placebo-controlled trials should be correctly conveyed [12–14].
2	Relapse of depression	Withdrawal symptoms may be mistaken for relapse [15,16]; no good evidence for advising long-term treatment [17–19]; depression usually remits spontaneously [20].
3	Chemical imbalance	No evidence for a chemical imbalance as a cause of depression, or for drugs fixing or correcting an imbalance of chemicals in the brain [19,21–23].
4	Functioning/Quality of life	No evidence that drugs help people return to work, reduce sick leave and improve their social relationships [19].
5	Sexual function	The drugs cause sexual dysfunction in many people, e.g. lack of libido and impotence [24].
6	Emotional numbing	The drugs may blunt people's emotions [25].
7	Suicidality	The drugs may increase the risk of suicidality, with no age limit [19,26–29].
8	Addiction	Objectively and subjectively, the drugs are addictive [30–32].
9	Withdrawal effects	The drugs may cause withdrawal effects, which may make it difficult for the patients to come off them [15,16,19,32].
10	Foetal harms	The drugs may cause neonatal abstinence syndrome [33]; it is less clear whether they may cause foetal malformations [34,35].
11	Duration of treatment	Randomised trials have only tested the drugs in the short term [19]. There is no evidence for their benefit in the long term [17,18].
12	Tapering	People must not stop the drugs suddenly [15]; a tapering is needed, often for a duration of many months [16,32,36].
13	Psychotherapy	Psychotherapy is effective [37,38] and may reduce the risk of suicide [39].
14	Off-label prescribing	The drugs are generally not approved for young people [40].

3.3. Chemical imbalance

Twenty-nine (74%) websites attributed depression to a "chemical imbalance" or claimed they could fix or correct that imbalance. Examples of misleading claims are shown in Table 5.

3.4. Functioning/Quality of life

Only two websites described the effect of antidepressants on functioning or quality of life. A Danish website wrote: "you may notice for example, that you sleep better at night and begin to take better care of yourself. You regularly eat, fix your hair, dress properly ... You tackle everyday tasks easier and you feel you have more energy and better appetite" [w34]. A UK website claimed antidepressants "have a good effect on your sex life as your mood lifts and you become interested in life and relationships again" [w19]. However, the same page stated that, "the side-effects of escitalopram might put a strain on your friendships and relationships, especially in the first few days of taking it" and that "you may have a lower sex drive" [w19].

Table 4

Number of websites passing our standards for scientific evidence and informed consent

	unN	Number of websites passing our standards for scientific evi	sites passinยู	g our stande	ards for sele	intific evide	nce and ink	ormed conse	int		
Information provided				Z	umber of w	Number of websites $(n = 39)$	39)				Total (%)
	AUS (n = 7)	$CA \\ (n=3)$	DEN $(n=2)$	IRE $(n=3)$	NZ $(n = 6)$	$ NOR \\ (n=2) $	SA $(n = 2)$	$ SWE \\ (n = 2) $	$ UK \\ (n = 5) $		
Effect	7	3	2	3	9	2	2	2	S	7	39 (100%)
Relapse of depression	3	7			3	2	2	1	3	4	22 (56%)
Chemical imbalance	5	3	2	2	4	_	2	2	2	9	29 (74%)
Functioning/Quality of life	0	0	_	0	0	0	0	0	_	0	2 (5%)
Sexual function	3	2	_	2	2	0	2	1	S	5	23 (59%)
Emotional numbing	П	0	_	0	_	_	_	0	0	0	5 (13%)
Suicidality	5	ю	_	2	7	2	_	0	4	5	25 (64%)
Addiction	0	0	0	0	0	1	0	0	0	0	1 (3%)
Withdrawal effects	9	3	2	_	4	_	_	1	S	4	28 (72%)
Foetal harms	0	0	0	_	_	0	_	0	S	5	13 (33%)
Duration of treatment	9	ю	2	_	33	2	2	2	4	4	29 (74%)
Tapering	33	2	2		2	1		1	4	3	20 (52%)
Psychotherapy	7	2		3	9	2	2	2	5	7	37 (95%)
Off-label prescribing	S	1	0	0	7	0	0	1	7	33	14 (36%)

Table 5 Examples of comments on biological causes of depression on websites

"Chemical imbalance"

Your body has chemicals in it that control your mood. Sometimes these chemicals get out of balance [w7]

Clinical depression is believed to be caused by a chemical imbalance in the brain [w8]

Depression can be triggered by external events in a person's life, or arise from biological or chemical changes in the body [w24]

It's a chemical imbalance in your brain that needs to be treated [w25]

In people with depression, it is thought that there may be an imbalance of these chemicals [w13]

An imbalance of chemicals (called neurotransmitters) in the brain can cause symptoms of a mental illness to emerge [w2]

Brain chemicals (neurotransmitters) play a mediating role in the development of depression [w4]

Chemicals in your brain called neurotransmitters may be out of balance [w]12

If you are depressed, these are out of balance and do not work properly [w36]

This may be due in part to the fact that the signals that control emotions in the brain decrease [w38]

Antidepressants fix or correct an imbalance

Medications help the brain to restore its usual chemical balance [w29]

Antidepressants work by restoring the brain's ability to use "feel good" chemicals [w30]

Antidepressants might be prescribed to help modify one's brain chemistry [w26]

Antidepressant drugs affect the functioning of signal substances in the brain and counteract the chemical imbalance [w34]

Antidepressant drugs affect and increase the activity of the neurotransmitters to restore balance [w39]

3.5. Emotional numbing

Five (13%) websites mentioned that antidepressants may cause emotional numbing. For example, one website stated that, "Some people report a general dulling of emotion while taking SSRIs [w5].

3.6. Sexual dysfunction

Twenty-three (59%) websites mentioned that antidepressants were associated with sexual dysfunction. For example, an Irish website stated that SSRIs are known to cause "low sex drive, lack of orgasm and, in men, abnormal erection or ejaculation" [w1].

3.7. Suicidality

Twenty-five (64%) websites mentioned that antidepressants may cause increased suicidal ideation, but 23 (92%) of them contained misleading or contradictory information related to this.

Some of the erroneous information was dangerous. For example, one website claimed that the association between antidepressants and suicidal risk "has not been proved" and that the FDA is still investigating the possibility of such a link [w5]. Another stated that, "there is no clear evidence of an increased risk of self-harm and suicidal thoughts in adults of 18 years or over" [w17], and one noted that taking antidepressants means that "you no longer think of suicide" [w37]. Another claimed that antidepressants "Prevent coercive thoughts and forced acts" [w35], which is also incorrect [19,26–29].

Only two websites mentioned the FDA's warning that the suicide risk may be observed in people of all ages [29]. Health Canada stated that, "new warnings indicate that patients of all ages taking these drugs

may experience behavioural and/or emotional changes that may put them at increased risk of self-harm or harm to others" [w13] and the US National Institutes of Mental Health recommended that, "the warnings from the US Food and Drug Administration (FDA) also says patients of all ages taking antidepressants should be watched closely, especially during the first few weeks of treatment" [w22] although this was not evident on the FDA website we included in our review.

One website acknowledged that, "there is a possibility that taking an antidepressant could make you feel suicidal – even if you didn't experience suicidal feelings before" [w18] whereas other websites, specifically aimed at "youths", did not mention the harms at all [w7, w30].

Thirteen of the 25 websites that mentioned the suicidal risk in patients misstated that the risk only occurs "when they first start to take antidepressants" or similar [w3, w9-10, w12-14, w18, w22, w27-28, w31-32, w36]. This is contradicted by evidence that the suicide risk increases whenever the dose is changed [16,19,29].

3.8. Withdrawal, tapering and addiction

Twenty-eight websites (72%) informed patients about the withdrawal effects caused by sudden cessation of antidepressants but 13 of these (46%) had misleading or incorrect information. For example, a Norwegian website stated that, "When you finish treatment, you sometimes get so-called withdrawal symptoms" but "it does not mean that you have become addicted" [w36]. A New Zealand website wrote that antidepressants "are very safe medications and are not addictive but need to be stopped gradually so that the body can adjust to not having them" [w8].

Twenty-three websites (59%) mentioned "addiction" with reference to antidepressants but 22 (96% of those) stated that SSRIs are not addictive. The remaining 16 websites did not make any reference to addiction at all. Only one of the 39 websites (3%), from Norway, acknowledged the addictive effects of antidepressants, warning that people using antidepressants "may get abstinence symptoms" [w36].

A Danish website with drug advertisements wrote that, "antidepressants cannot be abused ... and you experience no such hassle by taking them as you can experience with heroin" [w35]. An Australian website wrote that, "antidepressants are not addictive and you will not become dependent on them" [w29]. The website for the UK Royal College of Psychiatrists took it one step further and suggested that if people are having trouble stopping their medications, "Most doctors would say that it is more likely that the original condition has returned" [w17].

Only 20 websites (51%) warned patients to slowly taper the dose of their medication but 16 (80%) of these did not detail time frames.

3.9. Foetal harms in pregnancy

Thirteen (33%) websites mentioned the effects of antidepressants on foetal malformations or foetal withdrawal symptoms [w3, w4, w8, w15-19, w20-23, w25]. The remaining 26 websites either made no mention of the harms of antidepressants during pregnancy or suggested women consult their doctor.

3.10. Psychotherapy

Thirty-seven websites (95%) mentioned psychotherapy as an alternative or adjunct to medications. The websites contained varied levels of detail about talking therapies ranging from cognitive behavioural therapy (CBT) to interpersonal therapy, to group therapy.

3.11. Off-label use of drugs

Fourteen websites (36%) mentioned that SSRIs are prescribed off-label, meaning the medication is not approved for that condition. For example, in Australia, SSRIs are not approved for depression in people less than 18 years of age [40], yet many doctors prescribe the drugs for children.

4. Discussion

We found that the information about the benefits and harms of antidepressants on 39 popular websites contained information that conflicted with the scientific evidence.

4.1. Benefits

All websites suggested that antidepressants are effective or used to treat the symptoms of depression. However, none of them explained that the effect in randomised trials is so small that it is below the minimally clinically relevant effect [12–14,19] or might be non-existent because the trials have not been effectively blinded [13,19] or that the benefits could be outweighed by the harmful effects [12,19].

When the benefits were described with numbers, they were widely exaggerated, e.g. SSRIs "help to relieve symptoms of depression and anxiety in approximately 50 to 70% of people" [w9]. It is misleading to write that two-thirds of the patients taking antidepressants will recover [w30] or feel better [w29] because this reflects the spontaneous remission that would have occurred in any case, also in untreated patients [19,20].

4.2. Chemical imbalance

The marketing of depression as a "chemical imbalance" was widely promulgated by Eli Lilly, the makers of fluoxetine (Prozac) [21], the first widely used SSRI, and it has been very harmful. Despite being discredited many years ago [22,23], this myth appeared on three-quarters of the websites we examined. An Australian study showed that 88% of people think it's the likely cause of depression, and those who believe they have a "chemical imbalance" are more likely to take medication [41]. These false beliefs are likely to discourage people to eventually discontinue their SSRIs, particularly if they believe it is like needing insulin for diabetes [w29], the implication being that such conditions require treatment for life.

4.3. Withdrawal, addiction and relapse

What is called relapse of the depression is very often an abstinence depression, which consists of withdrawal symptoms that would not have occurred if the patient had not been on an antidepressant agent [15,16,19,31,32,36]. Psychiatrists often mistake these withdrawal symptoms for relapse [31,36].

The withdrawal reactions to SSRIs are very similar to those for benzodiazepines, which are widely acknowledged for their addictive properties [30]. It is therefore contradictory to claim that SSRIs are not addictive and the patients' experience is just the same: Once their body has adjusted to the medications, they often feel they have become addicted because they cannot get off the drugs again [16,19,31,32].

The effectiveness of antidepressants to prevent relapse is questionable. The STAR*D trial involving 4,041 patients found that only 3% of the patients who entered the trial remitted, and then stayed well and in the trial during the year-long follow-up [18]. There is no good evidence in support of patients

being advised to take antidepressants for 6-9 months or for their entire life [17–19], as suggested by many websites.

4.4. Suicidality

The increased risk of suicide caused by antidepressants in young people is well known. It is less well known that it has been shown in systematic reviews that this risk exists at all ages, including middle-aged women with urinary incontinence and healthy adult volunteers [19,27–29]. In 2007, the FDA upgraded its warning to include everyone under 25 years of age [42]. Yet, one website trivialised the black-box warning by stating that suicidality was rare and only observed in those "under the age of 18 years" [w35], and the UK Royal College of Psychiatrists claimed that, "There is no clear evidence of an increased risk of self-harm and suicidal thoughts in adults of 18 years or over" [w17].

Several websites had contradictory statements, including switching between scientific evidence and opinions. For example, the Mayo Clinic's website cited the 2007 FDA warning about the suicide risk [42] but undercut the message by stating that, "not all mental health researchers believe these warnings are necessary. Newer research indicates that the benefits of antidepressants may be greater than the risk of suicide" [w21]. Thus, the Mayo Clinic suggested that antidepressants protect against suicide, which is misinformation.

Several websites trivialised the harms by implying that suicidal and homicidal ideation or behaviour aren't as serious as suicide. The Mayo Clinic stated that, "None of the children in any of the studies actually took his or her own life" [w21], and the UK Royal College of Psychiatrists stated that, "There is some evidence of increased suicidal thoughts (although not actual suicidal acts)" [w17]. An Australian website, specifically aimed at a young audience, stated that, "The majority of young people who experience suicidal ideation will not go on to take their lives" [w28]. Using such logic, one might say that drunk driving is safe because most drunk drivers do not die in car crashes. There is a close link between suicidal events and suicide, and deliberate self-harm is one of the strongest predictors of suicide [43].

One argument for softening the warnings is to avoid deterring people from taking their medications. Such paternalism in lieu of honest information is common. For example, an Australian website [w28] blamed a drop in the use of antidepressants in the US on media publicity of the 2004 Black Box warning. However, the decline in the use of antidepressants had already begun in 2003 [44]. The argument that antidepressants protect children against suicide is based on flawed observational studies, and the proponents of this erroneous message consistently ignore observational data that demonstrate the opposite [19].

Several websites claimed that fluoxetine is safer than other SSRIs for young people, e.g. "Fluoxetine is considered to be safer than other antidepressants for people under the age of 18" [w19] and "Fluoxetine, an SSRI antidepressant, can be used in the under-18s" [w17]. However, this claim has been refuted [12]. Antidepressants for children are all unsafe.

4.5. Psychotherapy

Psychotherapy has less harms than antidepressants and is often superior, particularly in the long run [45,46], which is why we included it as one of the criteria for informed consent. Psychotherapy was mentioned on most websites, but the information varied considerably, from calling it very effective to only being effective in conjunction with antidepressants. A meta-analysis of ten trials showed that psychotherapy halved the occurrence of new suicide attempts in patients admitted after a suicide attempt

[39]. Since research suggests that antidepressants increase the risk of suicide in people of all ages [19,27–29] and have marginal benefits [12–14,19], we believe that psychotherapy should be the prevailing treatment for depression of all severities.

4.6. Limitations

Our study is limited to websites that ranked highly on Google searches from each country. On the other hand, this makes our results generalisable.

Conclusions

None of the websites met acceptable standards for informed consent or scientific evidence, and the information provided was sometimes contradictory within the same website. The widespread misinformation is likely to lead to inappropriate use and overuse of antidepressants and reduce the likelihood that people will seek better options like psychotherapy.

Author contributions

Both authors contributed to the concept, the protocol and extracting data. MD wrote the first draft of the manuscript. PCG revised the manuscript.

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None.

Data sharing statement

The data are freely available on the websites we studied.

Supplementary data

The supplementary files are available to download from http://dx.doi.org/10.3233/JRS-191023.

Conflicts of interest

None to report.

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