Analysis of consumer information brochures on osteoporosis prevention and treatment

Analyse von Verbraucher-Informationsbroschüren zu Osteoporoseprävention und -behandlung

Abstract

Purpose: Evidence-based consumer information is a prerequisite for informed decision making. So far, there are no reports on the quality of consumer information brochures on osteoporosis. In the present study we analysed brochures on osteoporosis available in Germany.

Method: All printed brochures from patient and consumer advocacy groups, physician and governmental organisations, health insurances, and pharmaceutical companies were initially collected in 2001, and updated in December 2004. Brochures were analysed by two independent researchers using 37 internationally proposed criteria addressing evidence-based content, risk communication, transparency of the development process, and layout and design.

Results: A total of 165 brochures were identified; 59 were included as they specifically targeted osteoporosis prevention and treatment. Most brochures were provided by pharmaceutical companies (n=25), followed by health insurances (n=11) and patient and consumer advocacy groups (n=11). Quality of brochures did not differ between providers. Only 1 brochure presented lifetime risk estimate; 4 mentioned natural course of osteoporosis. A balanced report on benefit versus lack of benefit was presented in 2 brochures and on benefit versus adverse effects in 8 brochures. Four brochures mentioned relative risk reduction, 1 reported absolute risk reduction through hormone replacement therapy (HRT). Out of 28 brochures accessed in 2004 10 still recommended HRT without discussing adverse effects. Transparency of the development process was limited: 25 brochures reported publication date, 26 cited author and only 1 references. In contrast, readability and design was generally good.

Conclusion: The quality of consumer brochures on osteoporosis in Germany is utterly inadequate. They fail to give evidence-based data on diagnosis and treatment options. Therefore, the material is not useful to enhance informed consumer choice.

Keywords: pamphlets, osteoporosis/prevention and control, decision making, evidence-based medicine

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Introduction

Recently, osteoporosis has become an issue increasingly covered by disease awareness campaigns. A popular example is the exhibition by the former Benetton photographer Olivero Toscani [1], displaying portraits of nude people, elderly and younger, suffering from osteoporosis. Such campaigns have been blamed as disease mongering [2]. There is no doubt that people require more information for decision making on preventive or treatment options. Ethical guidelines demand that evidence-based, clear and unbiased information are offered and made available to all patients and consumers [3]. Consumers' needs should be targeted, and best available evidence should be prepared using principles of risk communication and plain language [4], [5], [6].

Information brochures on osteoporosis prevention and treatment are widespread and readily available. Their suitability to support consumer decision making is not known. Therefore, we surveyed publicly available information brochures on osteoporosis in Germany using evidence-based criteria.

Methods

Brochures were initially collected in 2001, an update was made in December 2004. Written request was sent to patient and consumer advocacy groups, government organisations, medical associations, health insurances, and pharmaceutical companies. An internet search was performed in order to identify additional sources. Brochures were suitable for inclusion if they explicitly addressed patients or consumers, did not only present nutritional advice and did not cost more than € 3. Two reviewers (GM and AS) independently assessed the brochures, discrepancies were resolved by consensus. Thirty-seven criteria (Table 1 and 2) addressing content (n=17), transparency of the development process (n=7), layout and design (n=13) were used. The criteria were derived from publications by the General Medical Council of the United Kingdom [3] and the Harvard School of Public Health [5], and from former consumer information analyses [7], [8] and own work [6], [9].
Table 1: Content and transparency of the development process of 59 German consumer information brochures on osteoporosis

| Information provided                                      | No (%) of brochures |
|-----------------------------------------------------------|---------------------|
| **Content**                                               |                     |
| Natural course of osteoporosis                            | 4 (7)               |
| Risk of disease compared to other risks of daily living   | 1 (2)               |
| Balanced report on                                        |                     |
| Treatment benefit versus lack of benefit                  | 2 (3)               |
| Treatment benefit versus adverse effects                  | 8 (14)              |
| Lifetime risk of developing osteoporosis/related complications | 1 (2)               |
| Natural frequencies                                       | 1 (2)               |
| Strength of evidence                                      | 1 (2)               |
| Lack of evidence                                          | 3 (5)               |
| Absolute risk reduction                                   | 1 (2)               |
| Relative risk reduction                                   | 4 (7)               |
| Number needed to treat/to harm                            | 0                   |
| Estimates on screening tests                              |                     |
| Sensitivity/specificity                                   | 0                   |
| Predictive values                                         | 0                   |
| Medical, social, financial consequences of screening, diagnosis or treatment | 5 (8)               |
| Link to support and counselling                           | 41 (69)             |
| Further reading                                           | 36 (61)             |
| Readability†                                              | 54 (92)             |
| **Transparency of development process**                   |                     |
| Aim of the information                                    | 40 (68)             |
| Author                                                    | 26 (44)             |
| Publication date                                          | 25 (42)             |
| References                                                | 1 (2)               |
| Consumers’ involvement                                    | 1 (2)               |
| Financial disclosure‡                                      | 6 (18)              |
| Conflict of interest                                      | 0                   |

† Only financial consequences of bone mineral density measurement discussed
‡ Reviewers’ judgement, not assessed by readability formula
§ Out of 34 brochures by non-pharmaceutical providers
Table 2: Layout and design of 59 German consumer information brochures on osteoporosis

| Criterion fulfilled                                      | No (%) of brochures |
|----------------------------------------------------------|---------------------|
| Legible font style, e.g. Times New Roman                 | 48 (81)             |
| Appropriate space between lines (1.5 spacing)            | 54 (92)             |
| No words on shaded or patterned background              | 47 (80)             |
| Ample white space                                       | 50 (85)             |
| Appropriate length lines (< 12 cm)                      | 54 (92)             |
| Right margin jagged                                     | 24 (41)             |
| Words not splitted across two lines                     | 0                   |
| Consistency of design, no clutter                       | 55 (93)             |
| Guide for finding key information                       | 42 (71)             |
| Illustrations and charts clearly labelled*               | 35 (69)             |
| Graphics placed close to explanatory text               | 50 (98)             |
| Consistent and easily recognized headings               | 53 (90)             |
| Main points highlighted, e.g. bolded                    | 58 (98)             |

* Out of 51 brochures containing illustrations or charts

Results

A total of 165 brochures were identified, and 59 fulfilled the inclusion criteria. Twenty-eight brochures were excluded since they cost more than € 3 or did not explicitly address patients or consumers. 66 brochures did not specifically target osteoporosis prevention and treatment or only marginally discuss osteoporosis, and 12 brochures were replaced by an update in 2004. A list of excluded brochures is available from the authors on request. Table 3 displays the included material. Most brochures were provided by pharmaceutical companies (n=25), followed by health insurances (n=11), patient and consumer advocacy groups (n=11), government (n=3), medical organisations (n=3), and other providers (n=6). Independent agreement between the assessors was 97.9%. Table 1 shows the results of the analysis of the brochures’ content and transparency of the development process. Remarkably, 10 out of 28 brochures accessed in 2004 still recommended hormone replacement therapy (HRT) without discussion of increased overall risk through venous thromboembolism, heart attacks, strokes, and breast cancer [10]. At that time, the Drug Commission of the German Medical Association had already advised doctors to prescribe HRT only for particularly severe menopausal symptoms [11].

If mentioned, disease prevalence was commonly presented in a manner that is misleading such as “at least 6 to 8 million Germans suffer from osteoporosis” or “it affects every third woman aged over 50 years”. Only 1 brochure displayed the lifetime risk of hip fractures, the proportion of elderly remaining free from hip fracture, and the absolute risk reduction through HRT. Relative risk reduction was presented in 4 brochures, all referring to hip fracture reduction through external hip protectors. Financial consequences of screening on bone mineral density were mentioned in 5 brochures. The procedure is not covered by the German health insurances. Medical and social consequences of screening, diagnosis and treatment have not been discussed. All except 1 brochure failed to involve consumers within the development process. Transparency of the development process was poor. None of the brochures provided a declaration on conflict of interest. References were presented only by 1 brochure. Less than half of the material mentioned author and publication date.

In contrast, layout and design criteria were largely fulfilled (Table 2). Quality of brochures from patient and consumer advocacy groups did not differ from those from pharmaceutical companies and other providers. However, our sample may have been too small for such comparisons.
Table 3: Brochures included in the review (n=59)

| Provider                                      | Title                                                                 | Publication year |
|-----------------------------------------------|-----------------------------------------------------------------------|------------------|
| **Pharmaceutical companies**                  |                                                                       |                  |
| Aventis Pharma GmbH                           | Ratgeber für Osteoporose Patientinnen                                  | n. a.            |
|                                               | [Guidebook on osteoporosis for female patients]                        |                  |
| Azupharma GmbH & Co.                          | Osteoporose. Tipps zur Osteoporose-Vorbeugung [Osteoporosis. Tips on   | n. a.            |
|                                               | osteoporosis prevention]                                               |                  |
| Azupharma GmbH & Co.                          | Osteoporose. Patienteninformation [Osteoporosis. Patient information]  | 2000             |
| Boehringer Ingelheim                         | Was Sie über Osteoporose wissen sollten [What you should know about   | 1997             |
|                                               | osteoporosis]                                                          |                  |
| Henning Berlin, Sanofi-Synthelabo GmbH        | Anti-Aging für die Knochen [Anti-aging for the bones]                 | n. a.            |
| Henning Berlin, Sanofi-Synthelabo GmbH        | Patienten-Ratgeber Osteoporose [Patient guidebook osteoporosis]        | n. a.            |
| Hermes Arzneimittel GmbH                      | Denken Sie an Ihre Knochen [Remind your bones]                        | n. a.            |
| Hermes Arzneimittel GmbH                      | Osteoporose Risikotest [Osteoporosis risk assessment]                  | n. a.            |
| Hexal                                         | Osteoporose [Osteoporosis]                                             | n. a.            |
| Jenapharm                                     | Osteoporose. Informationen für Patienten [Osteoporosis. Patient      | n. a.            |
|                                               | information]                                                          |                  |
| Lilly Pharma                                  | Osteoporose: Risiko nach den Wechseljahren [Osteoporosis:              | n. a.            |
|                                               | postmenopausal risk]                                                   |                  |
| Merck dura GmbH                               | Aktiv gegen Osteoporose. Wegweiser zu starken Knochen [Active against  | n. a.            |
|                                               | osteoporosis. Guidepost to strong bones]                              |                  |
| MSD Sharp & Dohme GmbH                        | Es ist an der Zeit: Neue Wege, neue Chancen [The time is right: New   | n. a.            |
|                                               | ways, new chances]                                                     |                  |
| MSD Sharp & Dohme GmbH                        | Mit Schwung gegen die Osteoporose [Get going against osteoporosis]    | n. a.            |
| Opfermann Arzneimittel                        | Aufrecht ins Alter [Upstanding into old age]                          | n. a.            |
| Orion Pharma                                  | Was Sie über Osteoporose wissen sollten! [What you should know about  | 1999             |
|                                               | osteoporosis!]                                                         |                  |
| Orthomol GmbH                                 | Osteoporose: Knochenschwund rechtzeitig erkennen und vorbeugen [      | n. a.            |
|                                               | Osteoporosis: Early detection and prevention of bone loss]             |                  |
| Procter & Gamble Pharmaceuticals, Aventis     | Knochen stärken [Strengthen of bones]                                 | n. a.            |
| Pharma                                        |                                                                       |                  |
| Procter & Gamble Pharmaceuticals, Aventis     | Osteoporose geht uns alle an! [Osteoporosis does concern everybody!]  | n. a.            |
| Pharma                                        |                                                                       |                  |
| Procter & Gamble Pharmaceuticals              | Osteoporose. Erkennen Sie Ihr Osteoporose-Risiko [Osteoporosis.       | n. a.            |
|                                               | Identify your risk of osteoporosis]                                   |                  |
| Sandoz Pharmaceuticals GmbH                    | Osteoporose muss nicht sein [Osteoporosis can be helped]              | n. a.            |
| Solvay Arzneimittel                           | Osteoporoseschutz durch Östrogene [Protection of osteoporosis by      | n. a.            |
|                                               | estrogens]                                                            |                  |
Table 3: Brochures included in the review (n=59)

| Provider                                      | Title                                                                 | Publication year |
|-----------------------------------------------|----------------------------------------------------------------------|------------------|
| STADA                                         | Osteoporose. Frühzeitig erkennen – wirksam vorbeugen und behandeln  | n. a.            |
|                                               | [Osteoporosis. Early detection – effective prevention and treatment]|                  |
| Steierl-Pharma GmbH                           | Knochenaufbau und Osteoporose                                        | 2000             |
|                                               | [Ossification and osteoporosis]                                       |                  |
| Strathmann AG                                 | Starke Knochen – starke Muskeln                                      | n. a.            |
|                                               | [Strong bones – strong muscles]                                       |                  |

**Health insurances**

| Provider                                      | Title                                                                 | Publication year |
|-----------------------------------------------|----------------------------------------------------------------------|------------------|
| Allgemeine Ortskrankenkasse                   | Osteoporose [Osteoporosis]                                            | 2003             |
| Arbeiter-Ersatzkassen-Verband e.V.            | Osteoporose und Ernährung [Osteoporosis and nutrition]               | 1994             |
| Barmer Ersatzkasse                            | Gesund bis auf die Knochen [Healthy to the bones]                    | n. a.            |
| Betriebskrankenkasse                          | Osteoporose geht jede(n) etwas an [Osteoporosis does concern everybody] | n. a.            |
| Betriebskrankenkasse                          | Osteoporose vorbeugen. Gesunde Knochen im Alter [Preventing osteoporosis. Healthy bones in old age] | n. a.            |
| Gemeinnütziges Gesundheitsberatungszentrum der Betriebskrankenkasse Bayer | Osteoporose. Aufrecht älter werden. Ein Ratgeber zur Prävention von Osteoporose [Osteoporosis. Upstanding aging. A guidebook on osteoporosis prevention] | 1994             |
| Gmünder Ersatzkasse                           | Osteoporose. Der Kampf gegen den stillen Dieb [Osteoporosis. Fighting the silent thief] | 2002             |
| Hamburg Münchener Krankenkasse                | Osteoporose vorbeugen [Preventing osteoporosis]                      | n. a.            |
| Hamburgische Zimmererkrankenkasse             | Knochenschwund. Osteoporose. Entstehung – Vorbeugung – Behandlung [Bone loss. Osteoporosis. Development – prevention – treatment] | n. a.            |
| Innungskrankenkasse                           | Aktiv gegen Osteoporose [Active against osteoporosis]                | n. a.            |
| Techniker Krankenkasse                        | Osteoporose: Eine Information für Patienten und Angehörige [Osteoporosis: An information for patients and relatives] | 2004             |

**Patient or consumer advocacy groups**

| Provider                                      | Title                                                                 | Publication year |
|-----------------------------------------------|----------------------------------------------------------------------|------------------|
| Bundesverband Deutsche Schmerzhilfe e.V.     | Starke Knochen sind das Ziel [Strong bones are the aim]             | n. a.            |
| Bundessaelfhilfeverband für Osteoporose e.V. | Osteoporose und Ernährung [Osteoporosis and nutrition]               | 2004             |
| Bundessaelfhilfeverband für Osteoporose e.V. | Osteoporose beim Mann [Osteoporosis among men]                       | 2003             |
| Bundessaelfhilfeverband für Osteoporose e.V. | Osteoporose – was nun? [Osteoporosis – well then?]                   | 2004             |
| Deutsche Diabetesstiftung                    | Diabetiker Ratgeber: Osteoporose. [Diabetes guidebook: Osteoporosis] | 2000             |
| Deutsches Grünes Kreuz e.V.                  | Schmerztherapie bei Osteoporose [Pain therapy in osteoporosis]       | 2004             |
| Deutsches Grünes Kreuz e.V.                  | Osteoporose [Osteoporosis]                                           | 2003             |
Table 3: Brochures included in the review (n=59)

| Provider                                                                 | Title                                                                                           | Publication year |
|--------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------|------------------|
| Feministisches Frauen Gesundheitszentrum e.V. Berlin                     | Informationsmappe zum Thema Osteoporose [Information folder on osteoporosis]                    | available for all included articles† |
| Kuratorium Knochengesundheit e.V.                                        | Osteoporose rechtzeitig erkennen, richtig behandeln [Early detection and adequate treatment of osteoporosis] | n. a.            |
| Kuratorium Knochengesundheit e.V.                                        | Fit sein & fit bleiben Ihren Knochen zuliebe. Ein Präventionsratgeber [Be fit and stay fit for your bones' sake. A prevention guidebook] | 1999            |
| Kuratorium Knochengesundheit e.V.                                        | Osteoporose Patientenratgeber [Osteoporosis patient guidebook]                                  | 2000             |
| **Governmental organisations**                                            |                                                                                                 |                  |
| Bundesinstitut für gesundheitlichen Verbraucherschutz und Veterinärmedizin | Osteoporose. Aktiv gegen Knochenschwund [Osteoporosis. Active against bone loss]                | n. a.            |
| Bundeszentrale für gesundheitliche Aufklärung                            | Ernährungstip 16: Osteoporose – wenn Knochen müde werden [Nutritional tip No 16: Osteoporosis – when bones get tired] | 1994            |
| Gesundheitsamt Hannover                                                   | Osteoporose. Tipps für den Alltag [Osteoporosis. Tips for daily living]                         | 2000             |
| **Medical organisations**                                                |                                                                                                 |                  |
| Berufsverband der Ärzte für Orthopädie e.V.                             | Osteoporose – Ein Leitfaden für Patienten [Osteoporosis – a patient guide]                      | n. a.            |
| Berufsverband der Frauenärzte e.V.                                       | Osteoporose – Fragen und Antworten [Osteoporosis – Questions and answers]                       | n. a.            |
| Dachverband Deutschsprachiger Osteoporose-Selbsthilfeverbände und Patientenorientierter Osteoporose-Organisationen e.V., Dachverband der Deutschsprachigen Osteologischen Wissenschaftlichen Fachgesellschaften | Osteoporose Patientenleitlinie [Osteoporosis patient guideline]                                | 2003             |
| **Other providers**                                                      |                                                                                                 |                  |
| Arbeitsgemeinschaft zur Patienteninformation über Gesundheit und Umwelt e.V. | Sind die Knochen gesund, freut sich der Mensch. [Healthy bones please everybody]                | 2002             |
| Deutscher Reform-Verlag GmbH                                             | Ratgeber Osteoporose [Guidebook on osteoporosis]                                                | 2004             |
| Institut für Sporternährung e.V., Verein zur Förderung der gesunden Ernährung und Diätethik e.V. | Osteoporose. Vorbeugung durch richtige Ernährung und Bewegung [Osteoporosis. Prevention through adequate nutrition and exercise] | n. a.            |
| Govi Verlag                                                              | Osteoporose – Knochen schützen und stärken [Osteoporosis - protecting and strengthening bones] | 1997             |
| Landesapothekerverband Baden-Württemberg e.V.                           | Osteoporose. Tipps aus Ihrer Apotheke [Osteoporosis. Tips from your pharmacy]                   | n. a.            |
| Osteoporose-Forschungs- und Informationszentrum München                 | Neue Aspekte zur Krankheit Osteoporose: Ursachen, Diagnostik, Prävention [New aspects on osteoporosis: Causes, diagnostics, prevention] | 1997             |

† N. a. = not available because not mentioned within the brochure
‡ Folder consists of several articles
Discussion

Our results show that consumer brochures on osteoporosis prevention and treatment available in Germany do not fulfill internationally suggested criteria on evidence-based information and risk communication. Overall, the material assessed is not useful to enhance informed decision making since it is highly persuasive and misleading. Our results are supported by former studies on consumer information materials targeting other health issues. A recent analysis demonstrated that information on bone mineral density measurement available to consumers on the internet strongly differs from evidence coming from HTA reports. Consumer information was inaccurate and incomplete [12]. Analyses of pamphlets [8] and websites [7] on mammographic screening found that the information was poor and severely biased. In a previous study we demonstrated the deficiencies of consumer brochures dealing with screening for colorectal cancer [9]. Consequently, we developed an evidence-based information tool [13].

In recent years, osteoporosis has been recognised as an important area of research and intervention. Numerous preventive and treatment options have been suggested [14]. For consumers several issues of uncertainty remain such as limited predictive validity of bone mineral density measurement, marginal benefits of medication, and unknown long-term effects [15]. Therefore, osteoporosis prevention and treatment is a typical area for evidence based consumer information aimed to enhance decision making based on individual risk of disease, best external evidence and personal preferences. Ideally, such material should be produced by medical associations or advocacy groups. Suggestions have been made how to develop evidence-based consumer information [6], [16]. If these suggestions are feasible and acceptable beyond university institutions is still unknown.

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Notes

Authorship

All authors declare that they have substantially contributed to this paper and that they agree with the content and format of the manuscript.

Conflicts of interest

Gabriele Meyer, Anke Steckelberg, and Ingrid Mühlhauser all declare that they have no financial disclosures to make in relation to this paper. There were no sponsors for this project.
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