

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

Zusammenfassung

Ziel: Evidenzbasierte Informationen sind die Voraussetzung für informierte Entscheidungen von Verbrauchern bzw. Patienten. Die Qualität von Verbraucher-Informationsbroschüren zum Thema Osteoporose ist bislang nicht untersucht. In der vorliegenden Analyse wurde geprüft, ob die in Deutschland verfügbaren Broschüren geeignet sind, informierte Entscheidungen zu begünstigen.

Methoden: Selbsthilfegruppen und Verbrauchervertretungen, Gesundheitsministerien, Fachgesellschaften, Krankenkassen und Pharmafirmen wurden um Zusendung ihrer Osteoporosebroschüren gebeten. Eine erste Sammlung wurde 2001 durchgeführt, die Aktualisierung erfolgte im Dezember 2004. Die Beurteilung der eingeschlossenen Broschüren

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erfolgte durch zwei, voneinander unabhängige Untersucher anhand von 37 Kriterien zu Evidenzbasierung, Risikokommunikation, Transparenz des Entwicklungsprozesses, Layout und Gestaltung.

Ergebnisse: Insgesamt wurden 165 Broschüren identifiziert; 59 erfüllten die vorab definierten Einschlusskriterien. Die Mehrzahl wurde von Pharmafirmen herausgegeben (n=25), gefolgt von Krankenkassen (n=11) und Selbsthilfegruppen und -verbänden (n=11). Die Broschüren der verschiedenen Anbieter unterschieden sich nicht in ihrer Qualität. Nur 1 Broschüre präsentierte Angaben zum Lebenszeitrisko; in nur 4 Broschüren wurde der natürliche Verlauf der Osteoporose erwähnt. Eine ausgewogene Darstellung von Nutzen und fehlendem Nutzen bzw. Nutzen und unerwünschten Wirkungen von Therapieoptionen war in nur 2 bzw. 8 Broschüren gegeben. Vier Broschüren gaben die relative Risikoreduktion einer Therapieoption an, nur 1 Broschüre führte eine absolute Risikoreduktion durch Hormonersatztherapie (HET) an. In 10 von 28 im Jahr 2004 identifizierten Broschüren wurde immer noch die HET als Behandlungsoption empfohlen ohne die adversen Effekte zu diskutieren. Die Transparenz des Entwicklungsprozesses der Broschüren war gering: nur 25 Broschüren gaben das Publikationsdatum an, 26 nannten den Autor und nur 1 gab Literaturreferenzen an. Demgegenüber waren die Lesbarkeit und die Gestaltung durchgehend gut.

Schlussfolgerung: Die Qualität von Verbraucher-Informationsbroschüren zu Osteoporose in Deutschland ist völlig unzureichend. Sie sind nicht geeignet, informierte Entscheidungen zu unterstützen.

Schlüsselwörter: Informationsbroschüren für Verbraucher, Osteoporoseprävention und -behandlung, Informierte Entscheidung, Evidenzbasierte Medizin

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 [Guidebook on osteoporosis for female patients]	n. a.*
Azupharma GmbH & Co.	Osteoporose. Tipps zur Osteoporose-Vorbeugung [Osteoporosis. Tips on osteoporosis prevention]	n. a.
Azupharma GmbH & Co.	Osteoporose. Patienteninformation [Osteoporosis. Patient information]	2000
Boehringer Ingelheim	Was Sie über Osteoporose wissen sollten [What you should know about osteoporosis]	1997
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 information]	n. a.
Lilly Pharma	Osteoporose: Risiko nach den Wechseljahren [Osteoporosis: postmenopausal risk]	n. a.
Merck dura GmbH	Aktiv gegen Osteoporose. Wegweiser zu starken Knochen [Active against osteoporosis. Guidepost to strong bones]	n. a.
MSD Sharp & Dohme GmbH	Es ist an der Zeit: Neue Wege, neue Chancen [The time is right: New ways, new chances]	n. a.
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 osteoporosis!]	1999
Orthomol GmbH	Osteoporose: Knochenschwund rechtzeitig erkennen und vorbeugen [Osteoporosis: Early detection and prevention of bone loss]	n. a.
Procter & Gamble Pharmaceuticals, Aventis Pharma	Knochen stärken [Strengthen of bones]	n. a.
Procter & Gamble Pharmaceuticals, Aventis Pharma	Osteoporose geht uns alle an! [Osteoporosis does concern everybody!]	n. a.
Procter & Gamble Pharmaceuticals	Osteoporose. Erkennen Sie Ihr Osteoporose-Risiko [Osteoporosis. Identify your risk of osteoporosis]	n. a.
Sandoz Pharmaceuticals GmbH	Osteoporose muss nicht sein [Osteoporosis can be helped]	n. a.
Solvay Arzneimittel	Osteoporoseschutz durch Östrogene [Protection of osteoporosis by estrogen]	n. a.

(Continued)

Table 3: Brochures included in the review (n=59)

Provider	Title	Publication year
STADA	Osteoporose. Frühzeitig erkennen – wirksam vorbeugen und behandeln [Osteoporosis. Early detection – effective prevention and treatment]	n. a.
Steierl-Pharma GmbH	Knochenaufbau und Osteoporose [Ossification and osteoporosis]	2000
Strathmann AG	Starke Knochen – starke Muskeln [Strong bones – strong muscles]	n. a.
Health insurances		
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		
Bundesverband Deutsche Schmerzilfe e.V.	Starke Knochen sind das Ziel [Strong bones are the aim]	n. a.
Bundesselbsthilfeverband für Osteoporose e.V.	Osteoporose und Ernährung [Osteoporosis and nutrition]	2004
Bundesselbsthilfeverband für Osteoporose e.V.	Osteoporose beim Mann [Osteoporosis among men]	2003
Bundesselbsthilfeverband 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

(Continued)

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: Osteoporose – 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 Patienteninformati on 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 Diätetik 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 fulfil 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.

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.

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