

This Isn't Just A Phantom, Menopause, But You Can Vent Your Feelings - Qualitative Evaluation of Evidence Based Health Information (EBHI) Material

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Abstract

Objective: Because of the increased demand for the availability of independent information regarding the efficacy, the lack of efficacy and the possible harm of medical interventions, the study aims to evaluate the information package „Menopause" , published by the German Institute for Quality in Healthcare (IQWiG).

Methods: Qualitative, guideline-based interviews, carried out in n=41 women (40-63 years). The analysis of transcripts was carried out according to Mayring.

Results: Information perception of women who could use the material could be summarized into the following: (1) Information were perceived as independent and deemed trustworthy. (2) Scientific study results were unknown but welcomed. (3) Decision aids are useful but need further communicative support. (4) Women requested suggestions for empowerment and self-help. (5) Some women are better accessible through experiences. (6) Women who did not take on any information presented in the material. **Conclusions:** Through evidence-based health information (EBHI) and decision aids interviewed women can be enabled to make informed decisions concerning their health care. Health information should include the relevant context factors. However, not all women could be reached.

Practice implications: Not only the implementation of independent EBHI into the structure of healthcare but also communicative services including biographical aspects and self-help strategies are needed.

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Introduction

Background:

For years the availability of independent information regarding the efficacy, lack of efficacy and possible harm of medical interventions in order to enable the consumer to reach an informed decision regarding the treatment options in question has been demanded by patients and consumers. In Germany, following the health reformation of 2004 the development of generally comprehensible information regarding quality and efficiency as well as diagnostic and therapy of diseases with a substantial epidemiological meaning for all citizens was set up in paragraph 139b, SGB V by law as one of the assignments given to the Institute of Quality and Economy in Healthcare (IQWiG). This task is fulfilled by the IQWiG by producing information material which is freely accessible on their website (www.gesundheitsinformation.de). For the development of patient and consumer information the institute is guided by a previously unique objective: it is not to offer recommendations for treatment but rather to „increase critical health literacy of citizens in a sense of increasing cognitive and social competencies which destine the motivations and talents of an individual and aid to create access to information, to understand such information and to act accordingly in a way which improves and sustains health“¹. Furthermore, the institute adds to this objective one further dimension of empowerment which according to the definition by the WHO can be defined as “social, cultural and political processes by which individuals get to express their desires and needs, to present their issues, to define strategies for common decision-making processes and undertake political, social or cultural actions in order to meet those needs.”¹.

As an example of one of the central research areas we remind the reader of the movement of emancipated women years ago demanding access to information in regard to efficacy, lack of efficacy and risks of hormone therapy during menopause. Women felt misinformed. By insisting on independent information a long-term, critical, social debate was initiated which then led to the now largest randomized controlled study carrying out an investigation of an efficacy/risk-assessment of hormone therapy. Due to the negative results regarding the relationship of the costs-risks-ratio this then led to a drastic decrease of

hormone prescriptions. Similarly, the women’s health movement repeatedly drew attention to the strong influence of pharmaceutical interest in regard to the medicalization of the whole concept of menopause and the thus following importance of information independent from that of pharmaceutical companies².

The decrease of hormone prescriptions up to 2004 was significant, however, stagnated on that annual level in 2004 and later slightly increased again which leads to believe that the development of a guideline for informed decision-making still is necessary^{3,4}.

Objective of this study:

In 2006 an information package addressing the topic menopause was published on the internet pages of the IQWiG which consisted of five different modules (extensive review, leaflet, decision-aid manual, vignettes, video). The evaluation was carried out by the Bremen working group⁵ and is focused on the printed information given on those internet pages (excluding the video).

This qualitative study is assessing the extent to which information needs of potential users of the information material provided by IQWiG have been met and the extent to which the IQWiG was successful in supporting the participating women to make an informed decision based on the provided evidence-based information material. An initial publication merely deals in more depth with the decision-aid as part of an instrument used by IQWiG⁶.

Methods

The evaluation applied a qualitative study design. The data acquisition was carried out with the help of semi-structured interviews. For the a-priori sampling relevant influential factors were identified through literature research and experts’ interviews (age, hormone intake, residency in a prescription-rich or prescription-poor federal state in Germany, rural or urban region, educational qualification). The sample size was determined to include 40 interview participants. For the acquisition of interview participants different methods were utilized, particularly advertisements in local newspapers and regional information networks. The selection of interview participants was carried out based on the findings of the preliminary sample. For

further details see Mueller et al 2012⁶. The interviews were carried out in the participant's residency throughout a period of 14 days prior to which a printed version of the information package was mailed to them (without the movie part). Three researcher carried out the interviews, (MS, EM, BB).

The inter-observer differences were discussed within an interpretation group, discussing the material with all four researchers (MS, EM ,BB, NS).

The recorded and transcribed texts were interpreted separately as well as in interdisciplinary research workshops. The analysis of the interviews was carried out on the basis of the qualitative content analysis according to Mayring ⁷. Interviews took place after the research objective was explained in depth, information was provided regarding volunteering of participation and providing written consent. Data were saved in password-secured, external media. Due to ethical factors women who took hormones longer than 5 years were excluded from the study group. Specifically, the information regarding the efficacy of hormone replacement therapy contains a number of adverse effects and lack of proof of efficacies. It is possible that this information was previously not provided to the women during their prescription of medication. Thus, women who have been taking hormones for longer than 5 years were excluded from this study because a confrontation with the insecurities and adverse effect potential could have possibly unsettled and worried them to an extent that the researchers did not have an appropriate way of providing a crisis intervention.

Results

Between November 2007 and February 2008 a total of n=41 women who were undergoing menopause and resided in Lower Saxony (formerly in West Germany, n=21) and Saxony-Anhalt (formerly in East Germany, n=20) participated in the study of which 39 were used for analysis. Two interviews could not be used because of technical reasons.

Demographics:

The sample consisted of women with children (n=31) or without children (n=8), in a partnership / married (n=27), or without a steady partner (n=12), women with higher education or university degree (n=21), women with a completed vocational training (n=17) and women without a completed education (n=1).

Furthermore, women included in this study either reported to be suffering from severe symptoms (n=21) or reported to experience hardly any symptoms at all (n=18). They either worked full-time (n=14), part-time (n=15), were unemployed (n=7) or housewives (n=3). The age of included participants ranged between 40-63 years (Table 1).

Content-related evaluation:

Based on the material provided by the available data we could identify the following six categories: The first five of them are related to the perception of the material: (1) Information were perceived as independent and deemed trustworthy. (2) Scientific study results were unknown, but welcomed. (3) Decision aids are useful but need further communicative support. (4) Women missed information dealing with biographical aspects of the menopause and requested suggestions for empowerment and self-help. (5) Some women are better accessible through emotional aspects of experiences. Category (6) contains attitudes preventing the understanding or the use of the offered material, so that woman could not be reached: They are either looking for easy solutions, or regard menopause as developmental stage in their life time, or insist on a helpless attitude.

Information were perceived as independent and deemed trustworthy:

Evidence-based patient information including information about pros and cons of intervention are valued. The overall verdict regarding the information package „Menopause“ indicated a positive result from users. The wish to inform appropriately about pros and cons of hormone therapy was recognized. The material was judged by the women as professional, honest and trustworthy. From the interviewed women's point of view the following aspects contribute to being able to appraise the information as credible: the relinquishment of a clear instruction for action or rather recommendations in this regard, the reporting of advantages and disadvantages of the treatment options, statements regarding limited efficacy, application of numbers and study results, tables, referencing of sources and the confession to the limits of science (Table 2: number 1-3).

Table 1: Sample overview

	Hormone therapy with severe symptoms		Hormone Therapy without severe symptoms		No hormone therapy despite severe symptoms		No hormone therapy, no severe Symptoms	
	Urban area	Rural area	Urban area	Rural area	Urban area	Rural area	Urban area	Rural area
Qualification at school exit								
No school leaving qualification						S38		
Secondary school qualifications, 8./9. grade. POS; lower secondary school qualification	S35	N02			S30	N15, N03	S17	
Intermediate school qualification, 10. grade. POS; intermediate school qualification	S16, N08, N17	S08, N07		N06	S26	S03, N20	S31, S20, N14	S07, N16, N12
Highschool qualification, Technical diploma, EOS; higher school qualification	S24				N10	N11, N05		
College; University degree	S04, N01	S06	S09	S28	S34, N04, N19	S02, N13, N18	S01	N09

N stands for Niedersachsen – Lower Saxony and S stands for Sachsen – Saxony Anhalt

Table 2: Quotations of interviews

Category	Nº	Quotations (Interview number given in parentheses)
Information were perceived as independent and deemed trustworthy	1	„Well, I thought, that is what I also, what does it say, it all has been described quite honestly. I liked that ever so much. Now I am not quite sure whether I will find the section, well, whatever, there is no one and only right way. Meaning that there is no clear-cut pro and contra. I believe this keeps cropping up in various sections, doesn't it, that there is no real, that nothing gets really recommended" (N01, 103)
	2	“Yes. This is really the point, that they tell the truth and say that the truth is going to be presented here that it does not always help, not everything really helps. Not with everyone and. That one should not raise their hopes too much. You can try it but it was said truthfully I thought and I thought that it didn't say this is the remedy of choice and this is what you have to take and so on.” (S04, 286:287)
	3	„But instead to openly admit that we do not have the answers here. This is what I initially meant with ‚honest‘. This is just how it is. And you rarely read this kind of stuff, no matter what the information is, yes, that is usually lacking.” (N01, 341)
Scientifically-based patient information are unfamiliar	4	„Because studies also show that in about 5 out of 10 women who do not make use of any specific intervention menopausal symptoms cease by themselves. Well, then they present that. Five women are grey in those where they would have ceased by themselves anyways. Women whose hot flashes ceased due to hormone treatment. And in green those who still had hot flashes, despite hormone treatment. It is understandable. It's ok.” (S06, 139)
	5	„I've just now seen it differently (laughs). Yeah sure, generally they all discontinue at some point. But I think with the intake of the medication it stops quicker (...) Aha. (pause). Mmhhh, no this is not how I've seen it (laughs). (Confused) (...) Yes, yeah. But ehm, if you cannot rely on doctors anymore, well, who else can you trust?” (S16, 169:215)
	6	„And yeah, what else was there, women who still suffer from hot flashes despite hormone treatment. But to be honest, I cannot really imagine that. I mean, really.” (N01, 192)
Also decision-aids are unknown so far; but are either welcomed with pleasure or accepted after being offered some help	7	„Ehm, let's say it actually forces people to think about it, yes. And sometimes that is really ok. To think about it, about such things, do I take it or don't I and is there a risk involved, am I going to do this. (...) And there's nothing wrong if everyone was to do this.” (S30, 227:228)
	8	„Oh yes, in principle I quite like the concept. Since there is, you should deal with that kind of stuff and take time to work through it a little bit. At the end of the day it is about your own health. So I think that this is a good concept.” (N14, 214:220)
	9	„I played this through. Well, to be honest, I thought it was awesome. Well, there's this thing that accommodates me, doesn't it. (...) When I look at my result when I entered everything in the back I can say at first glance yes, that's exactly the way I see it. When I look at it purely from a pictorial perspective, exactly, that is my decision. Period. Yes, I can take that up (laughs). I really like it (laughs).” (N10, 143:155)
	10	„Mhm. I thought actually I do not need to have this in there anymore. Well, that's at least how it is for me. Because there's such a risk, for instance here. To assess a higher risk. What is worse. Is a stroke more impor... ahem worse than breast cancer. I recon everything, everything is bad. (...) Well, at least for me it isn't, I cannot weigh anything in this case.” N13 (203:207)

	11	„I mean now I know that many things aren't so nice and which risk it involves. But when you are stuck in a rut a bit like me, the kids are still little, and parents are old and at some point you go and work for 40 hours . I don't have time to try out anything – is exercise better for me or is diet better for me or am I supposed to try this tea or is that candle light nicer or so. (...) And that's how I feel, only someone with a lot of time on their hands can do that. As far as I'm concerned they can try it all out.“ (S28,7:10)
Users request more stimulation for self-help and empowerment as well as information regarding psychological and biographical aspects of Menopause	12	„That, I think needs to be presented much more positive. And there are those statements by women that are only sparse (...) well, at least for me that's a really important issue, what a woman can do about it. What I can do about it myself. (...) Like here, for instance, 4.3 it says relaxation techniques. Only really short that in regard to efficacy that no reliable judgment can be provided. And that's it, really. Susanne briefly said something else about it but that well, I guess I cannot really trust that any longer...“ (N13, 107)
	13	„Also, it is not a given that physical activity is useful but I think it at least helps to support the psychological condition. (...) Well, I do find it quite helpful, physical activity. I think they should definitely recommend that. You might not be able to measure it, necessarily. But I find that the body generally feels better and also the psychic.“ (N04, 132)
	14	„What I don't like is that sentence here: „No reliable judgment can be provided regarding the end result.“ I would certainly add to that that in any life phase relaxation can have a tremendous advantage, that's missing here, at least for me.“ (N06, 91)
	15	„Well, at least for me that's a really important point number 4, what a woman can do about it. What I can do about it myself.“ (N13, 107)
A number of women are accessible through emotional aspects of the accounted experiences rather than cognitive information	16	„Yeah, well, as I said before, it really is the same with the commentaries, I find it quite nice, simply so you can now, so that other women can orientate themselves and yeah, so that you can simply say „Nope, I can do this like...“ in your circle of acquaintances so that you can say I can openly talk about(...). That this isn't just a phantom, menopause, but that it is something clear and in grasp, you can vent your feelings, yes, there is something you can do about it. Somehow everyone has something to say and.“ (N11, 207)
	17	„And it's quite obvious that everyone is really dealing with this in a different way. That there is no one real solution for everyone but that the manifestations of the symptoms can vary quite a lot in regard to duration and intensity. (...)“ (N10, 214:215)
	18	„And actually, I also decided for myself after I read all that stuff here, you are in good company here, others also have, yes, that I recognize myself over and over again in these personal experiences, although they quite often repeat. But somehow it contains relatively much value of recognition.“ (N03, 156)
	19	„Yeah, well, I got from it that there are also many other people who feel the same, that they don't , they also have to get through this but some of them only with hormones others have decided against them but after all. Yes, you just have to get through this, no matter how. And you are not alone. (...) You are simply one of many others, that's all.“ (N03,162:164)
	20	„That you... well, that you shouldn't be bothered about all of this, the menopause, it is something natural that's how I understand it. Yes, some kind of statistic how this person is doing and that person.“ (S03, 45)

	21	„Yes, actually more in a general sense. Actually, you see yourself as a seeking person. Ehm, you take those bits that are good for you. (...) But with hindsight no matter what I’ve felt quite miserable for some time back then. (...) But thank God I have managed to leave this valley but only on my own accords. And sure, not everyone is able to do that all by herself. But then again, it was only possible with the help of many acquaintances where you can open conversations, well, very open. And when you have a few people of which you know that they are good friends, yes, like that, that’s how you can get out of it, sure.“ (S17, 35:63)
Women have not been reached by the material, because they are looking for easy solution OR regard menopause as a developmental stage of life OR find the material not relevant at all.	22	„Now I know that many things aren’t as nice and which risks there are but when one is stuck in a rut a bit like me, the kids are little and the parents are older and somehow you got to work 40 hours. I don’t have much time for experiments really, to see whether exercise is better or diet or whether I should try it with this tea or whether tea lights are prettier or soy.“ (S28, 07)
	23	„It’s pretty easy. Well, I did, yes in 2005 they determined that my joint pains had become worse. It took quite some time to manage them medicinally. And obviously I couldn’t be bothered having to deal with even more stuff. I need to function, I want to function and for that I need no heat waves that come over me every few minutes.“ (N02, 37)
	24	„But here it is apparent when they tell you a number of times that women aren’t only concerned about those symptoms but like here where she says, for instance, Susanne „I believe think menopause is a real crisis and one has to redefine oneself.“ You can actually compare that time with puberty. One has to regroup and reposition.“ (S07, 10:12)
	25	„Problems that in my opinion occur during menopause, farewell from life plans such as children, family, career. So there are certain emotions that reflect grieving about the things that weren’t done or that cannot be done anymore. But then there are also good thoughts. To live more consciously, being more laid back, appreciating the present more strongly, joy and pride regarding the things that have been achieved. Meaning that I did not restrict myself to the menopausal symptoms solely that were described in the article but more general, everyday issues, well this time in this age for myself, the thoughts that arose in me.“ (N10, 3)
	26	„This topic (of the information leaflet, remark by authors) moves me in some way. If I am honest that’s not like me at all. I don’t suffer from heat waves or uncontrollable sweating and no dryness of the vagina and. Well, considering this I don’t have any of these symptoms. I don’t need to, I don’t have to think about whether I should be taking hormones, do I. My train of thoughts resides elsewhere.“ (N10, 119)
	27	„Yes, I’ve tried quite a bit already. Well, first of all through the gynecologist, the things you can do apart from this Remifimin. I had already tried that and then I’ve had another kind, Femiklimin or Kliman or something like that, I still have that at home, the package. But really it was the same after all. It didn’t help me at all, no not at all.“ (N03, 128)
	28	„Well, at the moment I am so far that even after what I’ve read now, that actually made me, at the same time... we were at our wit’s end with what they could still do. There was just one more thing that I would have approached may be. But I will skip that for now. (...) Also, after that, this is what brought me, that happened simultaneously that for now I have to say none of this is really worth it.“ (N03, 336)

Scientifically-based information are unfamiliar:

Scientific study results were unknown to the participating women but appreciated. So far precise information regarding efficacy, lack of efficacy and possible harm of medical and complementary therapies based on scientific results are unfamiliar. As an example for the communication of study results interviewed participants were questioned about their understanding of a depicted graphic of the efficacy of hormone therapy in regard to the endpoint "hot flashes" (Figure 1). Such a type of communication is unusual. However, part of the users thought the precise preparation of scientific studies was a pleasant, sensible alternative to package inserts and requested such a presentation for all types of pharmaceuticals. Other comments show that the representation is not fully understood or not to the extent that was intended by the authors. The fact that for many women medications prescribed by the doctor are not effective because symptoms simply dissipate by themselves or even that despite application of medication will not result in a benefit but instead could possibly result in harm, may possibly be confusing. Thus, there are some readers who even doubt the statements provided in the information packet (Table 2: 4-6).

Decision-aids are unknown so far, but are either welcomed with pleasure or accepted after being offered communicative support:

The positive reactions to decision-aids illustrate the willingness of women to make decisions independently and in order to do that to make use of such kind of instruments. The decision-aids were perceived as a support to take time for these types of decisions. Decision-aids are interpreted as a sensible possibility for supplementing a conversation with the doctor which is often perceived as too short. Women expressed the wish to have available this type of decision-aids for other interventions in the healthcare system (Table 2: 7-8). Other women do not seem to think the decision-aid instrument is the right method for decision-making. They evaluate the decision-aid as confusing or incomprehensible and insufficient as a sole

source of information. Furthermore, the decision-aid was able to convey risks of hormone treatment but was not able to overturn the conflict between advantages and disadvantages of hormones (Table 2: 9-10).

An especially important function of the decision-aid is the invitation of users to actively contribute by developing their own rating for the respective advantages and risks of interventions; to weigh the advantages of the treatment options against the disadvantages against their own preferences. This invitation is being assessed differently by users. The instructions for weighting is felt to be helpful and practical since such a thorough preoccupation with the advantages and disadvantages of the interventions is demanded. Additionally, the wish was expressed to make it more clear that for decision making not only scientific study results but also subjective aspects (values, favors and dislikes) should influence the decision-making. Others felt the weighting was inappropriate for the risks to be discussed or expressed a further need for clarification or counseling (Table 2: 11).

Users request more stimulation for self-help and empowerment as well as information regarding psychological and biographical aspects of menopause:

Numerous questions of interview partners for menopause in regard to efficacy and risks of hormones are resolved, on the other hand some topic areas and questions cannot be answered satisfactory. The information is more focused on the medical terminology of menopause after sufficient scientific evidence exists for the ability to influence the occurrence of hot flashes with hormones. Less accounted for are the subjective symptomatic complaints of the readers. Due to the focused information based on scientific evidence they feel less recognized in their world of experience. The necessity for support and encouragement for an independent dealing with changes caused by or associated with the menopause (of physiological and psychological nature) is not sufficiently covered for all users given the information provided. Especially, the overcoming of emotional symptoms is not being addressed adequately. For other women the menopause is represented as a challenging biographical upheaval which needs to be processed and structured. Suggestions of this nature are being appreciated or their absence are also regretted. The representation of



Figure 1: Graphic and annotated text quoted from decision aid „Menopause“.

Observations out of 10 women experiencing hot flashes which either require an estrogen-preparation or an estrogen-gestagen-combined-preparation the following after 3-6 months:

- about 5 out of 10 women do not make use of any treatment, menopausal symptoms disappear “by themselves” (50%)
- about 3 women no longer experience hot flashes (30%) as a result of the treatment
- about 2 women still experience hot flashes (20%) despite hormonal treatment

alternative possibilities of dealing with menopause were welcomed; also the accounting for risks. The nature of communication of the current situation regarding scientific data for complementary medical methods was perceived as degrading and non-encouraging and thus was criticized as such. It was clear that for many women the use of alternative methods was not primarily about the reduction of hot flashes but much more about a general wellbeing and the feeling of being able to help oneself. A variety of positive experiences in this area were associated with diet, body therapies, exercise or even herbal and homeopathic therapies (Table 2: 12-15)

A number of women are accessible through emotional aspects of the accounted experiences rather than cognitive information:

Some users only read the personal experiences from other women and perceive them as helpful because partly they replace missing communicative exchange, produce a feeling of solidarity, address emotional aspects and moods or address attitudes. The conveying of messages through others produces the feeling that they are not alone with their experiences. Due to the heterogeneity of the presented personal experiences, their own mental state can be relativized. The stories of other women encourage and produce a feeling of solidarity: one is one of many others who feel the same or who feel similar in the same situation. The reports of personal experiences offer opportunities for identification (Table 2: 16-19).

Various emotional dimensions of concern can be addressed through reports of personal experiences. The feeling of emotional resonance enables encouragement and the ability to act. However, this reception of personal experience reports does not mean by far that the cognitive information has been fully accounted for (Table 2: 20-22).

Attitudes of women which could not be reached by the informational material:

Looking for an easy solution

This attitude is related to suffering from menopausal circumstances, but the need to manage family, job-related challenges, or other diseases and the unwillingness to spend time in discussion pros and cons of different treatment options. There is the need to avoid menopausal complaints. An easy solution has to be found. Therefore, EBHIs are rejected and the medical

advice of the doctor is regraded as an easy and good solution (Table 2: 22-23).

Menopause as a developmental stage of life

The information package is regarded as too focussed on medical aspects and neglecting developmental aspects of menopause as a normal life stage, which each woman has to face at some point in her lifetime. Medical information are regarded as important but not necessarily relevant for everybody. Some women feel confronted with the end of the reproductive phase of their lives and might feel forced to accept the missed opportunity of reproduction. Other women are talking about psychological aspects like depressions or intensive mood changes. They feel forced to re-evaluate their life and to find a new task when children leave the home. (Table 2: 24-26)

Resisting in helplessness

Other women perceive menopause as a time of suffering without help. For them there is no possibility to talk to somebody about this issue, and all trials to change something to the better are unsuccessful. If this kind of woman tries an intervention, she will soon drop it again. It will remain unclear, if this intervention is fitting to the symptoms. The ability to find verbal expressions for the concrete problem might be limited. A feeling of helplessness remains. Symptoms might not be limited to menopausal problems but to serious psychological problems. (Table 2: 27-28)

Discussion and Conclusion

Discussion:

This study enables a deeper understanding regarding the different ways in which evidence-based health information (EBHI) is received. The study was carried out as a qualitative study, revealing the different dimensions of use of this information material we can find in the German public. In order to find out to which extent each of this dimension exist we have to choose quantitative study designs. Nevertheless, our study results could help to improve the Health information homepage from IQWiG; it was relaunched in 2013 using plenty of evaluation results. However, these results could even be used for the development of further health information in general.

On one hand the enthusiasm in regard to trustworthy information attracts attention, on which

basis an informed decision can only be made in the first place. This information package represents a further fundamental development since in earlier qualitative studies the lack of high-quality and structured decision making aids were deplored⁸. It also shows that independent EBHI are namely an important foundation for the increase of critical health literacy competence. On the other hand EBHI are still quite unknown since they have not yet been implemented into healthcare structures. There is a demand which is increasingly expressed⁹ and different training formats are being developed to train consumers and health care professionals to use, develop and understand EBHI^{10,11}.

Criteria which were put forward by our interview partners to be indicators for the trustworthiness of the information are internationally regarded as ethical standards for the production of patient information. Also, the representation of efficacy, lack of efficacy and harm of hormone therapy in graphical form as a representation of study results is regarded as a standard for evidence-based patient information¹². It is surprising though that as opposed to the study by Glenton et al¹³ who assessed the perception of evidence-based patient information by users regarding the topic back pain issues that as this study found, scientific institutions and statistical information do not necessarily have to produce mistrust but can even generate trust.

The study by Hirschberg et al¹⁴ from 2013 under instruction of the IQWiG also analyzed a EBHI from the view of the users. Similarly, a variety of different types of receptions of the science-based information design was found here as well. Since narratives were not content of Hirschberg's evaluation, users' emotional needs as well as those perceived aspects that went beyond those of medical informative nature of the investigated issue went unnoticed. However, the authors specifically remarked on the lack of personal reference as a prerequisite for the better understanding and adaption of the EBHI.

A main remark from users perspective is, that they understood menopause not primarily as a medical problem but as a normal event in their life. They see it as a normal biographic episode with challenges to be mastered where medical support could be useful. Medical information should take into consideration the biographic perspective of life events like the menopause especially in times where personalized medicine plays a

more and more important role¹⁵.

Conclusion:

The offered information materials are mainly based on cognitive information, which many women hoped for and welcomed. However, other women were mainly seeking an exchange of experiences and satisfy their needs by means of the personal experience reports. The actual reception of personal experiences does not mean by far that an argument with cognitive information took place. Reports of personal experiences do enable an emotional identification and thus play an important role in patient information but so far could not be entirely recommended for a cognitive dispute for their efficacy or lack of hormones¹⁶.

On the other hand the very one-sided, objective pointing out of efficacy, lack of efficacy and possible harm of hormones without any emotional embedding could lead to unwanted reactions. This was previously shown in a study by Herber et al. where they investigated the reception of information in instruction leaflets of drugs¹⁷. An appropriate connection of the narrative level in correspondence with the cognitive needs of users seems to be useful. An example for the narrative level can be found at [www.Krankheitserfahrungen.de](http://krankheitserfahrungen.de) (<http://krankheitserfahrungen.de>) which was developed in close resemblance to the database of patient experiences (DIPEX)¹⁸. That way biographical dimensions of disease and the healing process could be made visible, which could appeal to patients on an emotional as well as cognitive level and the information access could be made easier.

The need for support and the dealing with subjective wellness dysfunctions and stimulation for self-help are also expressed by patients who were asked about their motives for seeking medical help from complementary therapists¹⁹. Thus, this need seems to be of importance to different groups of people. The discussion of the latest scientific findings in regard to complementary and self-help supplies should be carried forward in a more neutral tone. A rather process-oriented processing of menopausal-dependent changes seems to be desired. Recommendations for group counseling or group training can be provided which enable the coping with psychosocial aspects, a reduction

of menopausal symptoms and an increase of the knowledge and the options for action ²⁰.

Practice Implication:

The making of medical decisions under consideration of own preferences is unusual and requires a guideline and support (see IPDAS-criteria for the development of decision-aids ²¹). Information material which support independent decisions without wanting to push into one or the other direction, are rare. Possibilities of distribution and circulation should be sought and taken advantage of. Working with evidence-based decision-aids or process-oriented support of women during their menopause should be one component of the educational training of a variety of healthcare professions (healthcare, nursing, medical assistant). In the international context the implementation of 'decision coaches' is being tested in clinical processes ²². Decision coaches are representatives from a variety of healthcare professions who are specifically trained to accompany patients decision-aid processes. Curricula for decision coaches must include the ability to communicate scientific aspects on a cognitive basis. However, they also should include skills to meet emotional needs of customers in order to open them for the cognitive intentions of EBHIs. They also have to be aware of the biographical dimension of the individualised person and reflect relevante context factors of the concrete person. Finally, it should be emphasized as a limitation of the analysis that the studied sample in general was at a very high level of educational qualification. All the observations are true for this special sample of German women; women representing lower levels of education should be analyzed separately to extend the statements for the general population.

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