

REVIEW ARTICLE

Elicitation and Use of Patients' Preferences in the Treatment of Psoriasis: A Systematic ReviewNasir UMAR¹, Shelby YAMAMOTO¹, Adrian LOERBROKS¹ and Darcey TERRIS^{1,2}¹Mannheim Institute of Public Health, Social and Preventive Medicine, Universitätsmedizin Mannheim, Medical Faculty Mannheim, Heidelberg University, Mannheim, Germany, and ²Department of Health Policy and Management, College of Public Health, University of Georgia, Athens, Georgia, USA

There is a growing advocacy to incorporate patients' preferences in psoriasis treatment. The aim of this study was to critically review the scientific evidence regarding the elicitation and use of patients' preferences in psoriasis treatment. Published studies were systematically identified through PubMed, the Cochrane Library, the Web of Knowledge, and PsychINFO. Additional studies were identified by reviewing the reference lists of retrieved articles and through contact with experts in the field. Included studies involved the elicitation or use of patient preferences related to the treatment of psoriasis or psoriatic arthritis. Twenty-three studies were included in the review. The earliest articles were published in the 1980s. Patients' preferences were elicited for psoriasis treatment options, treatment attributes and for health state characteristics. Preferences were elicited from both patients and physicians. No study examined the use of patients' preferences in psoriasis treatment decision-making. The evidence demonstrates that patients' preferences relevant to psoriasis treatment are present and measurable. However, the potential use of those preferences has largely been ignored. *Key words: patient's preferences; patient's involvement; psoriasis; psoriasis arthritis; physician-patient relations; shared decision-making.*

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Nasir Umar, Mannheim Institute of Public Health, Social and Preventive Medicine, Universitätsmedizin Mannheim, Medical Faculty Mannheim, Heidelberg University, Ludwig-Krehl-Strasse 7-11, DE-68167 Mannheim, Germany. E-mail: nasir.umar@medma.uni-heidelberg.de

Psoriasis is a common, chronic inflammatory skin disease characterized by erythematous, papulosquamous lesions (1–4). According to the National Psoriasis Foundation approximately 2–3% of the world population is affected by this skin condition (3, 5, 6). Psoriasis causes significant morbidity and substantially affects health-related quality of life (7–9).

As psoriasis is often a life-long disease, the clinical goal is to find the most effective treatment with the fewest possible side-effects (10–12). However, focusing

solely on the outcomes of treatment may not be an efficient way to find the most effective, patient-acceptable treatment (13). Greater compliance and improved outcomes may be achieved if both treatment processes (e.g. treatment location, treatment frequency) and outcomes (e.g. side-effects, plaque reduction) are tailored to patients' preferences for treatment attributes and their psychosocial and employment contexts (14).

“Patient preference” here refers to the value an individual attaches to different treatment alternatives (e.g. treatment options) when faced with options to choose from (e.g. treatment A vs. treatment B) (15). The assumption is that individual preferences can be elicited using established preference elicitation methods, for example standard gamble (SG), time trade-off (TTO), person trade-off (PTO), willingness to pay (WTP) and discrete-choice experiments (DCE) (16, 17). Briefly, WTP involves asking patients how much they would be willing to pay for a hypothetical treatment that would alleviate their disease. How much the patients would be willing to pay is related to the level of health-related quality of life (HRQoL) impairment they experience (18). In TTO, patients are asked how many years of their life expectancy they would be willing to give up in order to receive a hypothetical treatment that would cure their disease for their remaining lifetime. The more life years the patients are willing to offer, the greater the level of impairment in their HRQoL (18). In SG, a patient is asked to make a choice between living in a particular health state with certainty or take a gamble with a medical intervention that has two possible uncertain outcomes, either achieving a health state that is better than the certain outcome (with a probability p) or worse outcome than the original (with probability $1-p$). The utility weight is derived through adjusting the probability p for a better health state until the subject is indifferent between the certain immediate outcome and the gamble (18). Visual analogue scale (VAS) involves asking patients, for example, to rate a certain health state on a scale ranging from 0 (death) to 100 (perfect health). Within the Quality of Life Years “QALY” framework, the rating derived from the VAS exercise is taken as the quality weight for that health state (18). In DCE, patients are asked to choose between different treatment options, each of which is decomposed into a

series of attributes and attribute categories or levels (i.e. features of treatment and ranges within each feature). From the DCE exercise, the values patients attach to different treatment attributes can be determined (18). More details on preference elicitation methods can be found in Ryan et al. (17).

There is a wide range of treatment options currently available for psoriasis treatment: local therapy, ultraviolet light (UV) irradiation, “classical” systemic therapeutics and, most recently, biologicals (12, 19, 20). Nonetheless, studies have reported treatment dissatisfaction, non-adherence and a sense of frustration among patients associated with their psoriasis treatment (21–23). In other patient groups, increased satisfaction with treatment has been demonstrated when patients’ preferences are incorporated into treatment decision-making (24–27).

Based on the positive outcomes observed in prior studies, there is growing demand from various stakeholders (e.g. patients groups, healthcare providers and researchers) to expand the use of patients’ preferences in treatment guidelines and disease management (24, 28–30). The aim of this study was to critically review and summarize the current evidence concerning the elicitation and use of patients’ preferences in psoriasis treatment, in order to determine the next steps needed to facilitate effective use of patients’ preferences in treatment decision-making.

MATERIALS AND METHODS

Whenever possible, the approach taken in this systematic review follows the new reporting guidelines: “Preferred reporting items for systematic reviews and meta-analyses” (PRISMA) (31) statement, an updated and expanded version of the “Quality of Reporting of Meta-analyses” (QUOROM) statement (32).

Criteria for study inclusion. Articles included in our review described empirical studies on psoriasis, psoriatic arthritis or treatment of these conditions that elicited preferences, used preferences, or both. No restrictions on study design or publication date were imposed. Study participants included psoriasis patients, psoriatic arthritis patients, physicians or members of the general population of any age who participated in studies that elicited or used preferences in relation to psoriasis treatment. Only articles written in English were included.

Criteria for exclusion. Editorials, letters, theses, commentaries and theoretical debates were excluded.

Search strategy

Data sources and search strategy. The search strategy was planned in advance and followed as described. Articles were initially identified by searching the following electronic databases: PubMed, PsychINFO via EBSCOhost, Web of Knowledge and The Cochrane Library. The search also covered the EMBASE database via the Cochrane Central Register of Controlled Trials. The databases were searched using keywords and MeSH terms, including: “patient preferences”, “shared decision-making”, “patient involvement”, “patient participation”, “patient satisfaction”, “physician-patient relation”, “der-

matologic agent”, “treatment outcomes” and “drug therapy”. Combining the above search terms with more specific terms, such as “psoriasis” or “psoriasis arthritis”, further refined the search. For example, the search string used in PubMed was (“Patient Preference”[MeSH Terms] OR (“Patient”[All Fields] AND “Preference”[All Fields]) OR “Patient Preference”[All Fields] OR (“Patient”[All Fields] AND “Preferences”[All Fields]) OR “Patient Preferences”[All Fields] OR “Patient Participation”[Mesh] OR “Physician-Patient Relations”[Mesh]) AND (“Therapy”[Subheading] OR “Drug Therapy”[All Fields] OR “Treatment”[All Fields] OR “Therapeutics”[MeSH Terms] OR “Therapeutics”[All Fields]) AND (“Psoriasis”[MeSH Terms] OR “Psoriasis”[All Fields])).

The online search was supplemented by hand searching the reference lists of the retrieved articles and by contact with experts in the field. The search was conducted between July and November 2009, with an updated search performed from August to October 2010. Two of the authors (NU) and (SY) developed and conducted the literature search.

Study selection. The title and abstract of any identified articles were first screened for eligibility, with full text publication of all potential articles subsequently retrieved for further assessment. NU and SY independently performed the eligibility assessment of the retrieved articles. Disagreements about eligibility assessment were resolved through discussion until consensus was achieved.

Data collection and analysis

Outcome measures. The focus of the preference elicitation activity (e.g. treatment options, treatment attributes, health states, or health state domains) was the primary outcome measure abstracted from the studies. As secondary outcomes, we also extracted the preference elicitation method used (binary or paired comparison; ordinal scale, visual analogue scale, or other forms of ranking; willingness to pay; time trade-off; standard gamble; or discrete choice experiment) and the purpose for the preference elicitation (i.e. how the preferences were used in the study). If consistency in the study participants, study focus (e.g. preference elicitation for health states, health state domains, treatments, or treatment attributes) and preference elicitation method were observed, our goal was to compute summary measures for the preferences assessed.

Data collection process. A data extraction form was developed based on the Centre for Reviews and Dissemination (CRD) templates (33). The data fields contained in the data extraction form included information on study authors, sample size, sex, mean or median age, study setting, study country, study design, publication date, preferences assessed, preference elicitation methods used, preference outcomes and major findings. The form was pilot-tested on 5 of the included studies and then revised based on this experience to improve its appropriateness across the studies reviewed. NU and SY independently extracted the data from the included studies using the data extraction form. Disagreements in data extraction and interpretation were resolved through discussion until consensus was achieved.

Data items. In addition to the primary and secondary outcomes described above, data were collected on the study sample (sample size, mean or median age, sex, patient group or physician), study setting, country and study design, as well as the publication date of the included articles.

Synthesis of results and summary measures. Due to the heterogeneous nature of the included studies and the variability of the outcome measures it was not possible to compute summary measures for study outcomes as planned. Consequently, qualitative methods (narrative) and descriptive measures (frequencies and percentages) were used to summarize and present our results.

RESULTS

Study selection and characteristics

Out of the 919 articles originally identified (i.e. 912 article citations, 5 articles identified through the reference lists of retrieved articles and two articles suggested by experts in the field), 885 were excluded during the preliminary screening phase (Fig. 1). After retrieval and review of the remaining 34 studies, a further 11 articles did not meet the inclusion criteria and were subsequently excluded. This left a total of 23 articles that were included in the review (see Fig. 1). Due to the limited number of articles identified and the observed variation in the focus and method of the preference elicitation reported, we chose not to compute summary measures. Instead, we deviated from our initial study protocol by taking a qualitative approach to synthesize our results, as shown below.

For several studies (43%), preference elicitation was a secondary or supporting objective of the overall study goals. Although the preferences of patients with psoriasis have been studied since the early 1980s, none of the reviewed studies reported the use of patient preferences in psoriasis management. Four of the studies (17%) used a clinical outcome measure (e.g. Psoriasis Area Severity Index (PASI) and Psoriasis Disability Index (PDI)). The sophistication of elicitation techniques has evolved over time from binary questions (preferred or not) to more theoretically grounded methods, such as discrete choice experiments and standard gamble (see Table SI; available from: <http://www.medicaljournals.se/acta/content/?doi=10.2340/00015555-1304> for more details on study characteristics).

Synthesis of evidence

The review of the extracted data identified 4 areas of focus for the preference elicitation activities related to

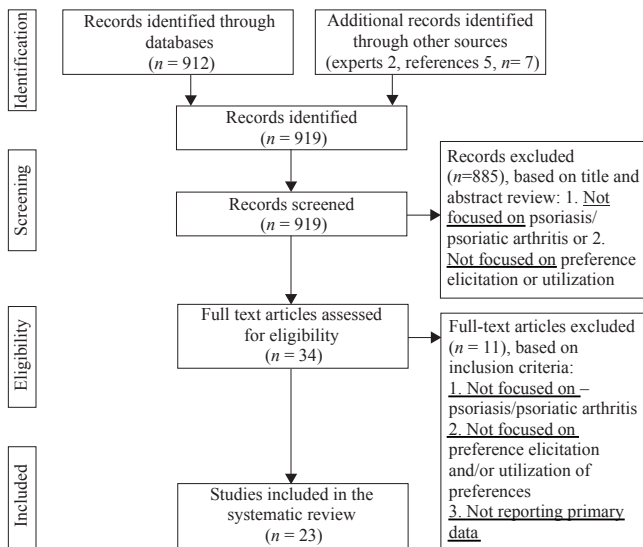


Fig. 1. Systematic literature review of preferences studies related to psoriasis management (until 2010).

psoriasis and psoriasis arthritis. Specifically, patients' preferences were elicited for psoriasis treatment options (33% of studies), treatment attributes (48% of studies), for different health states (11% of studies) and for different health state domains (8% of studies). A more detailed description of these foci follows.

Preferences for treatment options. Some of the earliest preference elicitation studies identified (i.e. dating back to 1984) were concerned with the elicitation of patient preferences for different treatment options (34–41). For example, patients were asked to state their preferences with regard to two different ointments (34, 35, 38), two different creams (36), a cream vs. an ointment (42), phototherapy with two different lamps (43), and bath psoralen plus UVA phototherapy (PUVA) vs. oral PUVA (44). Furthermore, patients demonstrated clear preferences regarding the characteristics of different treatment options. For example, patients found some creams to be messy (40, 46), or the mode of drug administration to be inconvenient, which may ultimately affect patients' treatment adherence (14). Patients with moderate to severe psoriasis also indicated clear preferences for oral therapies (e.g. methotrexate) over phototherapy (e.g. PUVA) (45). Under the assumption of comparable clinical effectiveness, patients preferred treatment with methotrexate to ciclosporin (45). In another study, patient expressed preferences for bath PUVA over oral PUVA (48). In all of these studies, patients were able to state which treatment options they most preferred or if they were indifferent (i.e. had no preference) between the options (34–36, 40, 43).

Preferences for attributes of treatment. In several studies preferences were not elicited for specific therapies, but for the attributes of treatments (Table SII; available from: <http://www.medicaljournals.se/acta/content/?doi=10.2340/00015555-1304>). For example, patients were able to express their willingness to trade process attributes, such as the frequency of drug administration (45) and access to a physician (46), or outcome attributes, such as treatment benefits (7, 23, 40) and avoidance of potential adverse effects (7, 23). Specifically, patients traded less frequent treatment two times weekly narrow-band ultraviolet B (NB-UVB) in favour of three times weekly NB-UVB treatment, because the three times weekly treatment clears chronic psoriasis faster (49). Furthermore, psoriasis patients expressed preferences for telemedicine to in-person visit if telemedicine provides quicker access to their physician (50). Patients' preferences were also elicited to determine their valuation of different drug formulations (14, 41, 47). In one study, patients were found to prefer foams and solutions to cream, gel and ointments (14). The assessment of preferences for time of drug administration found no significant difference between patients' preference for day-time and night-time application of vehicles (14). Preferences for treatment attributes were

also elicited from physicians. Dermatologists were also found to trade between treatments attributes (e.g. time to moderate improvement, risk of adverse effects, and time to relapse) when recommending treatments (7). In particular, dermatologists considered the risk of liver damage to be the most important adverse event influencing their choice of treatment, followed by the risk of skin cancer and high blood pressure (7).

Preferences for different health states. Results from the included studies showed that patients have measurable preferences for different health states associated with psoriasis (48). Most often, health states were assessed using utility scores assigned by patients to different levels of psoriasis severity, with a higher utility score associated with a more preferred health state (48). In the study by Schmitt et al. (49), patients were willing to accept an approximately 40% shorter life expectancy to avoid uncontrolled psoriasis. Lundberg et al. (40) found that patients were willing to pay up to 9–14% of their mean personal income to be free of psoriasis. In addition, the health state utilities measured for psoriasis patients were shown to correlate with patients' self-reported quality of life (18, 40, 48), with a decrease in patients willingness-to-pay corresponding to improvement in self-reported quality of life (18). In the study by Zug et al. (48), patients assigned lower utilities for severe psoriasis than moderate psoriasis, and the utilities for both severe and moderate psoriasis were less than the utility values assigned for mild psoriasis. Zug et al. (48) also found that patients' demographics, for example age, gender or education, were not predictive of patients' preferences for different health states. Overall, patients attached a wide range of utilities (value) for each health state. In other words, the values patients reported differed both within and between health states (40, 48).

Preferences for different health state domains. Patient preferences were also elicited to determine the value attached by psoriasis patients to different health state domains (50, 51). In general, physical comfort, emotional health and social comfort were highly ranked and concentration was the least ranked health domain for psoriasis patients (50). For example, the median amount (interquartile range (IQR)), patients were willing to pay for a hypothetical cure of psoriasis specific to a particular domain was USD 2,000 (500–5,500) for physical comfort, USD 2,000 (250–5,000) for emotional health, USD 1,000 (300–3,000) for social comfort, and USD 875 (25–3,850) for ability to concentrate (54). For psoriatic arthritis patients, however, physical comfort, work, sleep and self-care were the most valued health state domains, with social comfort as the lowest ranked domain (51). For example, the median amount patients were willing to pay for a hypothetical cure of psoriasis specific to a particular domain was USD 10,000 (5,000–75,000) for physical comfort,

USD 10,000 (2,000–50,000) for work, USD 10,000 (5,000–50,000) for sleep, USD 9,500 (2,500–50,000) for self-care, and USD 2,000 (25–10,000) for social comfort (55). The value attached to various health state domains measured the relative impact of domain-specific HRQoL on patients.

Methods used to elicit preferences from psoriasis patients

A variety of methods was used to elicit preferences in the included studies (see Table SII). For example, preferences were elicited using VAS, rating, ranking and ordinal scales. In early studies (pre-1990), preferences were most often measured in a binary fashion (i.e. asking the patients to state their preferences or choose their most preferred option). In later studies, however, elicited preferences using more theoretically grounded methods such as "standard gamble" (SG), "time trade-off" (TTO) and "willingness-to-pay" (WTP) were more commonly observed. The most frequently used method was WTP, which was used in 8 of the studies (40, 42, 46, 49–53), followed by TTO, which was used in 5 of the studies (40, 48, 49, 52, 53). "Discrete choice experiments" (DCE) was used in 3 studies (7, 23, 47) and SG was used in 2 studies (40, 48). Preferences (utilities) derived from these methods may differ. For example, preference scores from SG and TTO are more closely similar than those obtained from VAS. This suggests that SG and TTO measure similar aspects of patients' preference. The ease of application of these methods also varies. Results from the included studies showed that patients found it easier to use methods such as TTO, PTO than SG (48). Furthermore, there are limitations associated with these methods. For example, WTP may be biased by individual ability to pay, i.e. respondents with more money may be willing to pay more for a treatment (52).

DISCUSSION

Although the preferences of patients with psoriasis have been studied since the early 1980s, none of the reviewed studies reported on the use of patient preferences in psoriasis management. As a result, additional evidence is needed to support the growing advocacy to acknowledge patients' preferences in psoriasis treatment decision-making and guidelines.

Effective use of patients' preferences in shared decision-making has been associated with positive findings in other patient groups (27, 54, 55). For example, in a previous study investigating the influence of the match between patients' preferences for information vs. information received, Auerbach and colleagues reported that the attending surgeon and resident doctor rated patients as adjusting better during surgery when the information provided before surgery matched patients'

preferences for information (56). Patients were also found to experience less anxiety and be more adaptive during an invasive medical procedure (catheterization) when provided with information matched to patients' preferences (57). Patients' adjusted better during surgery, had lower self-reported pain and reported better satisfaction when their preferences were actualized (57). Recognizing patients' preferences for information (or not), has further been found to have significant effects on patients' symptoms of anxiety and depression. Similarly, the match between patients' preferences for involvement vs. enacted involvement in decision-making was found to have significant, positive effects on patients' satisfaction with care processes (58–61) and treatment anxiety (58).

Incorporating psoriasis patients' preferences in treatment recommendations may improve therapy adherence and increase the likelihood that positive outcomes are achieved. To facilitate the recognition of psoriasis patients' preferences in treatment decision-making, however, future studies should go beyond elicitation to investigate the impact of recognizing patients' preferences in treatment decision-making on patient outcomes. Furthermore, only 4 out of the 23 studies reviewed used clinical measures such as PASI and PDI. It has been shown that PASI is one of the most important clinical tools available for objectively assessing the magnitude of benefit resulting from a psoriasis treatment (62). Future studies should therefore employ clinical measures, since dermatologists emphasize the importance of clinically observable criteria (e.g. lesion clearance) (63). In addition to improving dermatologists' acceptance through the use of clinical tools, employing validated, objective measures alongside self-reports allows for better quantitative evaluation and correlation of patient outcomes. Finally, as cross-sectional research cannot disentangle the temporal sequence between events and outcomes, future studies should consider longitudinal, repeated measure study designs.

To the best of our knowledge, this is the first review that explicitly examines the elicitation and use of patient preferences in the treatment of psoriasis. However, this review is not without limitations. Specifically, only published articles were considered, and then only articles written in English, which could potentially introduce reporting bias into our data collection. To address this issue, we worked to increase the comprehensiveness of our search by using multiple databases and contact with experts in the field. Nonetheless, we may have missed a relevant study using our search strategy or due to inconsistent search terms in literature databases, a common limitation in methodological reviews (64). However, exhaustiveness is most important in standard effectiveness reviews such as Cochrane reviews (64). Finally, we found no established criteria fully suited to assess the study quality or the risk of bias in preference

elicitation studies, a concern also expressed by Opmeer et al. (16).

Although the results of this study demonstrated that preferences among psoriasis patients are measurable, many of the included studies had small sample sizes, which calls into question the generalizability of their results (65). Small sample size may produce exaggerated effect sizes, increasing the chances that significant differences are falsely positive (65). The general small sample sizes of the studies included in our review could therefore be a source of bias and should be considered in interpretation of our findings. In addition, computing summary measures (i.e. meta-level statistics) was not possible due to the varied nature of the outcomes measured in the studies. For example, some studies used more than 3 preference elicitation techniques and measured different outcomes. As a result, we employed a qualitative approach and descriptive measures to synthesize our results. This is not unique to our review, but is rather common in methodological reviews (64). However, as the literature and interest in eliciting and using patient preferences in treatment decisions continues to grow, meta-level analysis may become possible to summarize and facilitate use of the evidence (66).

Finally, there are some controversies surrounding preference elicitation, including the validity and stability of elicited preferences over time (67) and ethical problems attributed to the use of preference elicitation results. For example, when making clinical decisions for particular patient groups, the use of aggregated preferences scores obtained from preference elicitation methods may disregard the opinion of those with scores that significantly deviate from the mean, a phenomena referred to as the "tyranny of the majority" (68, 69). This ethical problem has undermined the validity of cost-utility analysis as a basis of resource allocation decisions (70). Nonetheless, preference elicitation has become a popular research tool for determining the value patients place on different health states or treatment options (67).

Conclusion

Patients with psoriasis demonstrate significant preferences for multiple facets of their health state and disease management. The potential to improve care through the use of patient preferences, however, has been largely ignored. We can only hypothesize, based on the evidence for other patient groups, that effective use of patient preferences in psoriasis treatment decision-making would likely improve both patients' satisfaction with treatment and objective clinical outcomes.

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