Quality of Life

29

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Introduction

The World Health Organization (WHO) defines the quality of life (QoL) as '*an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment*' (https://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/). QoL in dermatology is becoming increasingly important, especially as the severity of the impact is now used as a criterion for access to specialised medications (e.g. high-cost drugs, biologics). In addition, QoL is a useful parameter to measure during treatment to monitor success.

Dermatological disease is associated with a high psychosocial burden, which inevitably impacts QoL. Outcome measures for QoL in dermatology patients should ideally consider the condition, age of the patient and psychosocial impact (including impact on families). There are several validated tools available for measuring QoL, both generic (i.e. across specialties) and disease/condition-specific in dermatology. It remains unclear which instruments are preferred. Standardising the use of outcome measures is important to allow comparisons between studies on QoL in dermatology.

Psychological/psychiatric co-morbidities are diagnoses that occur alongside the primary diagnosis for which the patient is referred (e.g. anxiety, low mood, depression), and can also impact the quality of life for patients, their families/carers.

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QoL in dermatology is assessed using generic, dermatology-specific and/or disease-specific measures. Table 29.1 lists commonly used generic QOL measures. Generic measures assess QoL for any condition, they are useful to compare QoL outcomes for people across specialties (e.g. impact on QoL of psoriasis versus asthma). Table 29.2 lists commonly used dermatology-specific QOL measures. Measures specific to dermatology (or dermatology-specific measures) can be used across any dermatological condition and allow comparisons to made between them; however, they do not consider disease-specific issues that are important to patients (Prinsen et al. 2013). The most widely used dermatology-specific QoL tool is the Dermatology Life Quality Index (DLQI) (Finlay and Khan 1994); other measures are the Dermatology Quality of Life Scales (DQOLS) (Morgan et al. 1997), Dermatology-Specific Quality of Life Instrument (Anderson and Rajagopalan 1997), Skindex-29 (Chren et al. 1997a) and 17 (Nijsten et al. 2006). Table 29.3 lists commonly used disease-specific Quality of Life measures. Disease-specific tools measure the impact on QoL for specific conditions in dermatology (e.g. psoriasis, vitiligo, atopic dermatitis) and take into account disease-specific characteristics.

There is a lack of consensus on the use of QoL measures in dermatology (Prinsen et al. 2013; Chren et al. 1997b). When selecting an instrument consider the following:

- What are you trying to measure?
- Does the instrument take disease-specific characteristics into account?
- Is it patient or physician-dependent?
- Will the patient be able to complete it (language barrier, literacy)?
- Is it burdensome to complete in an outpatient setting (consider asking the patient to complete prior to appointment, or afterwards)?
- The recommended strategy is to combine a generic dermatology and disease-specific measure (Both et al. 2007)

1. *Considering the psychosocial impact of dermatological disease*

Dermatological disease can affect many aspects of a patient's life and their self-perception. Although often interrelated and overlapping, psychosocial impacts to consider include:

- Feelings of embarrassment
- Decreased confidence and self-esteem
- Fears of stigma or rejection
- Social anxiety or social withdrawal
- Ethnic and cultural issues
- Secondary psychiatric co-morbidities, e.g. depression or anxiety
- Physical functioning
- Sleep disturbance
- Restrictions on family responsibilities

Table 29.1 Generic HRQoL instruments

QoL measure	Brief description	Total number of items	Domains assessed	Completion time
EuroQoL 5-Dimension (EQ-5D) (Group E 1990)	• One of the most commonly used HRQoL measurements in population health studies, clinical practice and clinical research • Two sections: a descriptive system with three levels to self-rate (no problems, some problems and severe problems) and a visual analogue scale for respondents to report their overall health status (worst to best health imaginable) • The first section is coded into a five-digit number: 11111 (no problems in all dimensions) and 33333 (severe problems in all dimensions) The numerals have no arithmetic properties • 243 different health states from the coded scoring possible, but ceiling effects present and lack sensitivity for changes with minor morbidity. • 171 languages versions available	Two parts: five items and a visual analogue scale	Mobility Self-care Usual activities Pain/discomfort Anxiety/depression	1 min
Medical Outcomes Study 36-item Short Form Health Survey (SF-36) (Brazier et al. 1992)	• Designed for and frequently used in epidemiological and clinical research. • Eight scaled scores which are coded, summed and translated onto a scale of 0–100 (worst and best health, respectively) • Includes a question on a subjectively perceived change in health and one on an impression of positive health “full of life” • 50+ language versions available and extensive testing for cultural equivalence • Two shorter versions: SF-6 and SF-12 are available	36 items	Physical functioning Social functioning Role limitations due to physical problems Role limitations due to emotional problems General health Vitality Mental health Bodily pain	5–10 min

(continued)

Table 29.1 (continued)

Nottingham Health Profile (NHP) (Hunt et al. 1980)	• Simple questionnaire format with subjective binary item responses (“yes/no”) allowing quick self-administration but reduced sensitivity to minor impairments and unable to track deteriorations or improvements in individual items • Sleep included but the social domain is underestimated • Results presented as a profile rather than an overall score • Optional second part on particular life areas including occupation, housework, family life and hobbies	38 items	Energy level Physical mobility Sleep Emotional reaction Pain Social isolation	5–10 min
Sickness Impact Profile (SIP) (Bergner et al. 1981)	• Prioritises the objectively measurable impact of illness on daily activities and behaviours. Less focus on the mental aspects and subjective components of diseases e.g. pain scoring • Clear focus on disability so most suited to use in patients with mobility impairments (e.g. psoriatic arthropathy.) A ceiling effect is present in general population samples and patients with mild disabilities and is less responsive to mild changes • Items are weighted based on the level of dysfunction. The scores are converted onto a 0–100 scale can be calculated for each separate domain, group or as an overall score	136 items	*Physical dimension:* Ambulation Mobility Body care and movement *Psychosocial dimension:* Social interaction Communication Emotional behaviour Alertness behaviour *Independent Categories:* Sleep and rest Eating Work Home management Recreation and pastime	20–30 min

Table 29.1 (continued)

World Health Organisation Quality of Life assessment (WHOQOL-100) (WHOQOL 1998)	• Assesses overall QOL rather than being restricted to HRQoL • The 100 items (each to be rated on a five-point scale) included creates a significant time burden for the respondent but the ease of the scoring algorithm keeps the administrative burden relatively low • Prospectively designed across 15 health centres worldwide. Good discriminant validity, reliability and responsiveness demonstrated in UK and USA populations • A shorter version (WHOQOL-26) combines one item from each of the WHOQOL-100's 24 facets with two benchmark items for overall QoL and general health	100 items	Physical Psychological Level of independence Social relationships Environment Spirituality	30 min

Glossary: *QoL* quality of life, *HRQoL* health-related quality of life

Table 29.2 Dermatology-specific HRQoL instruments

QoL measure	Brief description	Total number of items	Domains assessed	Completion time
Dermatology Life Quality Index (DLQI) (Finlay and Khan 1994)	• First and most commonly used dermatology-specific instrument • Uses a four-point Likert scale for each of the 10 items. A composite score (0–30) is calculated by summing the score of each question. The higher the score, the more the QoL is impaired • Multiple versions are available including translations and an illustrated family and children's version. Scoring may be affected by nationality	10	Symptoms and feelings Daily activities Leisure Work and school Personal relationships Treatment	5 min

(continued)

Table 29.2 (continued)

Skindex-29 (Chren et al. 1997c)	• Assesses the frequency of each item over the previous 4 weeks (never, rarely, sometimes, often, all the time) Designed to assess changes over time and includes item on adverse effects of treatment • Responses for each domain are averaged and transformed into a linear scale of 100, (0 = no effect and 100 = all the time.) A single composite score can be calculated but its validity is unclear • Multiple other versions available including the SkinDex-teen (for adolescents)	29	Symptoms Emotions Functioning	5–10 min
Skindex-16 (Chren et al. 2001)	• A modified one-page version of the Skindex-29 which measures bother rather than frequency of the respondent's experiences • Responses are given on a three-point scale	17	Psychosocial Symptoms	2 min
Dermatology Quality of Life Scales (DQoLS) (Morgan et al. 1997)	• Developed in a single UK outpatient dermatology department to assess the impact of dermatological conditions on patients' psychosocial states and everyday activities • Has not been used frequently in cross-sectional studies	41	Dermatological symptoms Physical activities Psychosocial state	5–10 min

Table 29.2 (continued)

Dermatology-Specific Quality of Life Instrument (DSQL) (Anderson and Rajagopalan 1997)	• Developed from the SF-36, with a focus on acne and contact dermatitis. Not typically used for other conditions. • Easy to use format. The first set of questions use a score of intensity or satisfaction of 1–10. The second set uses a five-point ordinal score assessing frequency over the past month. A final score is summed from adding all the items	52	Dermatologic symptoms Physical activities Psychosocial state	10–15 min
Children Dermatology Life Quality Index (CDLQI) (Lewis-Jones and Finlay 1995)	• A short illustrated questionnaire designed for children (4–16 years) • Contains 10 questions (each on a four-point Likert scale) covering the impact of their skin disease and its treatment on their everyday activities and psychosocial state • An overall score is calculated by summing the score of each question. This is on a linear scale from 0 to 30, the higher the score the greater the impact on their QoL • The Teenager QoL index (T-QoL), an 18 item equivalent is available for teenagers (12–19 years)	10	Symptoms Feelings Leisure time School and holidays Relationships Sleep Treatment impact	2–3 min
Family Dermatology Life Quality Index (FDLQI) (Basra et al. 2007)	• Used to assess the secondary impact of a child's skin condition on the QOL of adult family members. Can also be used for the partner of an adult patient • Uses 10 items, each on a four-point Likert scale • An overall score of 0–30 can be calculated by summing the responses. The higher the score the greater the impact on family members	10	Physical well-being Emotional distress Relationships Household responsibilities Leisure time and hobbies Finance Ability to work/ study	2–3 min

Table 29.3 Disease-specific HRQoL instruments

QoL measure	Brief description	Total number of items	Domains assessed	Completion time
Psoriasis Disability Index (PDI) (Lewis and Finlay 2005)	• A subjective questionnaire to be completed by the patient using a 4 week recall period to quantify the level of handicap experienced by patients with psoriasis. It has been translated into at least 16 languages and has been used in published research in 20 countries. Recognised by NICE • 15 questions each with four options (not at all, a little, a lot, very much) scored on a scale of 0–3. Total score is creating by summing the scores of each item. The higher the overall score the more the QoL is impaired	15	Daily activities Work or school or alternative questions Personal relationships Leisure Treatment	3–5 min
Psoriasis Index of Quality of Life (PSORIQoL) (McKenna et al. 2003)	• Specifically designed to measure QoL in psoriasis. Shown to be a practical, reliable and valid instrument for measuring the impact of psoriasis on QoL and recognised for use by NICE. • Consists of 25 questions in a true/not true format. Ever positive response is score 1 point and the individuals points of summed into a final score (maximum 25) with higher scores indicating worse QoL	25	Self-consciousness Problems with socialising Physical contact and intimacy Limitations on personal freedom Impaired relaxation and sleep Emotional stability	3–5 min
Quality of Life Index for Atopic dermatitis (QoLIAD) (Whalley et al. 2004)	• 25 item questionnaire commonly used to measure the impact of atopic dermatitis on a patient's QoL. Available in several languages • Binary responses in yes or no format for each question with each answer recorded as "yes" scoring 1. The higher the final summed score the worse the QoL	25		2 min

Table 29.3 (continued)

Infants' Dermatitis Quality of Life Index (Lewis-Jones et al. 2001)	• Designed for use in infants with atopic dermatitis below the age of 4 years. Is be completed by the child's parent or regular carer • The Infants' Dermatitis Quality of Life Index is calculated by summing the score of each question creating a total from 0 to 30. The higher the score, the more the QoL is impaired	10	Symptoms Daily life Activity limitations Emotions	2 min
Acne-Specific Quality of Life Questionnaire (AcneQoL) (Gupta et al. 1998)	• Developed and validated for use in clinical trials. Confirmed to be responsive, internally consistent, and valid • Patient-completed questionnaire with a 1-week recall period composed of 19 items in four subscales. The responses of each item are summed to yield four overall domain scores. A higher score represents a higher quality of life	19	Self-perception Role-emotional Role-social Symptoms	3–5 min
RosaQOL (Nicholson et al. 2007)	• Developed for acne rosacea to be specific for subjective disease burden related to rosacea and sensitive to changes in the disease over time • Reponses to each item score on a scale from 1 (never) to 5 (always). The higher the overall score, the worse the HRQoL	23	Emotions Functioning Symptoms	3–5 min

(continued)

Table 29.3 (continued)

Melasma Quality of Life Scale (MELASQOL) (Balkrishnan et al. 2003)	• Developed from other questionnaires to prioritise the emotional and psychosocial aspects of melasma (in female patients) with higher discriminatory value compare to other general scoring instruments • Uses a seven-point Likert scale ranging from 0 (not bothered at all) to 7 (bothered all the time). The answers are summed together to provide an overall score, with higher scores representing a poorer quality of life	10	Emotional well-being Social life Recreation and leisure	2–3 min
VitiQol (Lilly et al. 2013)	• Developed to assess the impact of vitiligo on the patient's QoL • Uses a seven-point Likert score ranging from 0 (never) to 6 (all the time) for the first 15 items to assess frequency. With scores that the patient reports for each item added to yield a total score. The final item is a seven-point Likert score which asks the patient to self-rate the severity of their vitiligo	16	Participation limitation Stigma Behaviour	2–3 min
Chronic Urticaria Quality of Life Questionnaire (CU-QOL) (Baiardini et al. 2005)	• A validated tool developed to detect the impact of chronic urticaria on subjective well-being and QoL • An easy to use format with each item being scored on a five-point Likert scale. The scores are then summed to create an overall score	23	Physical symptoms Impact on life activities Sleep problems Embarrassment Limits	5 min

- Limitations on recreational activities, leisure time or holidays
- Financial implications, e.g. reduced ability to work or occupational restrictions, cost of treatments

2. *Why ask about QoL?*

Specific consideration of QoL can improve patient care and service delivery in a number of ways. These are summarised below:

Reason	Examples
To inform clinical decision making and the consultation	• Improving shared decision making • Setting appropriate treatment aims • Guiding dose adjustments and use of clinical guidelines • Informing referral or discharge decisions
To improve communication between the patient and clinician	• QoL scoring systems provide a quick method for the clinician to see the subjective impact of the skin condition on different dimensions of the patient's QoL (some of which may not frequently be asked about) • High or low scores can then prompt further discussion of these areas.
For awareness of skin disease burden	• Prompts the patient to consider areas of their life which may be impacted that are not often asked about • For the clinician to gain an understanding of the patient's experience and skin-related QoL—which may often not correlate with skin lesion burden
For clinical service development	• For audit and quality improvement purposes • To inform clinical guideline development • For education purposes through improved understanding of the impact of skin disease

3. *How to start asking patients about their QoL*

Validated generic or dermatology-specific QoL questionnaires provide accurate tools to record, track and compare perceived QoL.

> However, useful screening questions to open up a discussion about the patient's QoL include:
>
> - Do you find that your skin condition affects your quality of life?
> - It is common for skin conditions to have an impact on mood, is this something that you have experienced?
> - Is there anything that you would like to do but are unable to or find difficult to do because of your skin condition?
> - Do you find that your skin condition or its treatments interfere with your daily activities, responsibilities or ability to work?

- Do you find that your skin condition interferes with your family or social life? Your ability to build or maintain relationships?
- Does your skin condition interfere or stop you from doing activities that you find fun or fulfilling?

4. *So your patient reports a poor QOL?*

When helping a patient with a poor QoL, identified either through conversation or by using a QoL measurement tool, there are a number of questions we recommend considering.

Consider:

- Is their skin disease a key negative driver behind their poor-quality of life or are there any other contributing factors?
- Has a QoL score been recorded previously? What is the trend and what may be contributing to any change?
- Are there other related co-morbidities? Consideration of anxiety and depression is required.
  - The Hospital Anxiety and Depression Scale (HADS) can be used as a valid screening tool.
  - Could treatments being used, e.g. steroids or retinoids, be contributing to a recent change in mood?
- Is the patient at risk of suicidal behaviour?
  - Patients should be asked directly about this. There is no evidence that asking these questions increases suicide risk.
  - If yes, a risk assessment should be completed and the patient referred to an appropriate team as per local guidelines and their risk assessment. These teams may include: their GP, liaison psychiatry or a local crisis team
- What is the patient's view on how they can improve their QoL?

Take action to improve QoL

There is a bi-directional relationship between physical and mental health. Optimise disease management, bearing in mind potential negative implications of the treatment itself, e.g. time requirements which could lead to further limitations of social and work activities. It is important to include the patient in this discussion.

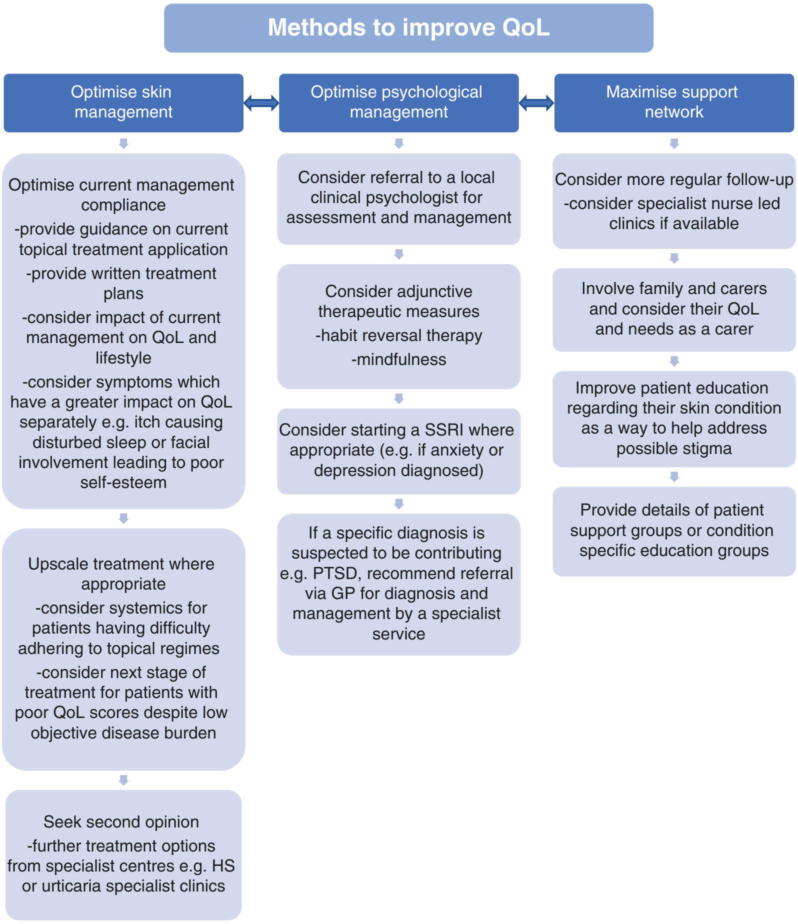
Alongside this, consider the patient's psychosocial well-being. This may involve referral to other clinical teams such as a clinical psychologist for assessment and to start target treatments (e.g. cognitive behavioural therapy or habit reversal therapy). You should also consider starting the patient on an SSRI if the patient has significant anxiety or depression. Starting an SSRI requires monitoring and may have associated risks. It may be appropriate to start treatment in conjunction with the patient's family doctor who may also be able to refer patients for evidence-based psychological therapies in the community such as Talking Therapies or the IAPT (Improving Access to Psychological Therapies) programme.

5. *How to improve QoL in dermatology patients*

Practice Point

Completed QoL scores should prompt a dialogue during the consultation where specific QoL domains which are rated particularly adversely or have had a marked difference since the previous score are discussed to determine contributing factors and prioritise a management plan. Recording the total score alone misses the opportunity for valuable insight and may reduce patient motivation to complete another score if nothing clearly happens.

When aiming to improve patients' QoL, there are three main aspects of management which are listed below. These should be managed simultaneously. The flow chart does not need to be followed in order, it instead provides a list of options to be considered and moved between.



Optimise current management compliance
-provide guidance on current topical treatment application
-provide written treatment plans
-consider impact of current management on QoL and lifestyle
-consider symptoms which have a greater impact on QoL separately e.g. itch causing disturbed sleep or facial involvement leading to poor self-esteem

Upscale treatment where appropriate
-consider systemics for patients having difficulty adhering to topical regimes
-consider next stage of treatment for patients with poor QoL scores despite low objective disease burden

Seek second opinion
-further treatment options from specialist centres e.g. HS or urticaria specialist clinics

Consider referral to a local clinical psychologist for assessment and management

Consider adjunctive therapeutic measures
-habit reversal therapy
-mindfulness

Consider starting a SSRI where appropriate (e.g. if anxiety or depression diagnosed)

If a specific diagnosis is suspected to be contributing e.g. PTSD, recommend referral via GP for diagnosis and management by a specialist service

Consider more regular follow-up
-consider specialist nurse led clinics if available

Involve family and carers and consider their QoL and needs as a carer

Improve patient education regarding their skin condition as a way to help address possible stigma

Provide details of patient support groups or condition specific education groups

6. *QoL of family members and caregivers*

It is important to also consider the impact of the patient's dermatological disease on their caregiver's QoL and family function. This is relevant for both adult and paediatric patients who rely on family members or other carers for either repeated emotional or physical (e.g. help with treatment administration) support.

Caring for a family member with skin disease can be very time consuming, which can have negative impacts on personal relationships, psychosocial functioning and cause sleep disturbance. An individual's ability to work may be restricted due to care commitments and they may need to take unplanned leave to care for a sick child.

A number of validated carer QoL scales exist. Commonly used generic scales include The Adult Carer Quality of Life Questionnaire (AC-QOL). The Family Dermatology Life Quality Index (FDLQI) has been created to acknowledge the specific needs of carers supporting a patient with dermatological disease, and the potential impact of the dermatological disease on family function. Carer QoL scales are also being developed for specific conditions, such as the Dermatitis Family Impact Scale. Further details of these tools are documented in the QoL tool summary tables.

Practice Point

Anxiety and depression were found to have a 36% prevalence in caregivers of children with either atopic dermatitis or psoriasis in a recent study. Both of these can reduce the ability of the caregiver to support the patient, and prevention or treatment of these may help skin disease management.

Use of a validated caregiver QoL scale for consideration of the burden on caregivers is important to identify negative impacts on different domains (psychosocial, relationships, financial.) Poor caregiver QoL scores may require consideration of more intensive treatment or additional support for the caregiver.

7. *Role of QoL assessment in access to high-cost treatments*

QoL measurements also have an impact on the availability of treatment options and management decisions.

Many national guidelines require minimum DLQI scores before certain treatments are available. These include:

NICE Guidelines including DLQI scores as criteria for funding

Drug	Condition	Criteria
Adalimumab, Etanercept	Plaque psoriasis	• DLQI > 10 for commencing treatment • 5 point reduction in DLQI at 16w (adalimumab) and 12w (etanercept)
Infliximab	Plaque psoriasis	• DLQI > 18 for commencing treatment • 5 point reduction in DLQI at 10w

NICE Guidelines including DLQI scores as criteria for funding		
Drug	Condition	Criteria
Il-17a inhibitors e.g. Ixekizumab	Plaque psoriasis	• DLQI > 10 for commencing treatment • 5 point reduction in DLQI at 12w
Apremilast	Plaque psoriasis	• DLQI > 10 for commencing treatment • 5 point reduction in DLQI at 12w
Dupilumab	Atopic dermatitis	• 4 point reduction in DLQI at 16w
Alitretinoin	Chronic hand eczema	• DLQI > 15 for commencing treatment

8. *Interpretation of calculated DLQI scores*

How to interpret DLQI scores	
0–1	No effect at all on the patient's life
2–5	Small effect on patient's life
6–10	Moderate effect on patient's life
11–20	Very large effect on patient's life
21–30	Extremely large effect on patient's life

9. *Tools available to measure QOL*

Commonly used outcome measures for QoL are summarised in Tables 29.1–29.3.

Practice Point
Use both a generic QoL questionnaire as well as a condition-specific QoL questionnaire when considering QoL. Generic scales allow comparisons with other conditions and may be required for treatment guidelines, whereas condition-specific scales may allow more precise consideration of all dimensions of the patient's life that may be affected as a result of their specific skin condition.

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