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Patient and clinician perspectives of information needs concerning oral epithelial dysplasia

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Abstract

Objectives: Individuals diagnosed with a chronic oral disease that increase the risk of mouth cancer, such as oral epithelial dysplasia (OED), require appropriate knowledge to make informed decisions. The present study aimed to assess whether patient information needs of a group of patients concerning dysplasia were met and to what degree clinicians agree with patients on 'important' topics.

Subjects and Methods: This represented secondary analyses of a cross-sectional study to assess the information needs of 86 patients diagnosed with dysplasia compared with those of 77 clinicians using the validated OED Information Needs Questionnaire. Descriptive, concordance and regression analyses were performed for the collected data.

Results: The mean and median total scores for all items in the amount of information received subscale were 2.33 and 2.44, indicating overall unmet needs concerning dysplasia. Clinicians were generally able to predict topics of greatest importance to patients, although their scores were mainly lower than those of patients ($k=0.06$). There was a higher agreement between patients ($k=0.25$) than clinicians ($k=0.09$).

Conclusion: Clinicians are encouraged to assess a patient's information needs to ensure tailored and patient-centred communication concerning OED during all clinical consultations.

KEYWORDS
information needs, mouth neoplasms, patient preference, physician–patient communication, precancerous conditions

1 | INTRODUCTION

Histopathologically diagnosed oral epithelial dysplasia (OED) has an annual increased risk of malignant transformation of 1.7%–3.5% (Iocca et al., 2020). OED is usually caused or driven by tobacco and/or alcohol, the use of betel nut preparations, pre-existing inflammation such as oral lichen planus and rarely by haematinic deficiency or genetic disease (e.g. Fanconi's anaemia). Associations with oncogenic types of human papillomavirus (HPV) are probable but have yet to be conclusively demonstrated (Porter et al., 2018). Despite the removal of clinical and histopathological apparent disease and cessation of any causative factors (particularly tobacco) patients can remain at risk of further disease for many years and require appropriate clinical monitoring (Iocca et al., 2020; Nankivell et al., 2012).

As a consequence of the chronic and sometimes uncertain behaviour of OED, patients and their carers require to have appropriate knowledge to lessen future risks, be aware of a change that warrants the attention of their attending clinicians and have the motivation to robustly attend review appointments. Focusing on 'what the patient with OED wants to know?' emphasises the importance of adopting

the term 'concordance', which has often now replaces other terms used in a similar context such as 'compliance', 'adherence' and 'cooperation' (Mullen, 1997; Segal, 2007). The latter terms were criticised as they may not focus upon the patient's wish for their health-related decision-making, but possibly a concession to the expectations of the healthcare professionals (HCPs) (Horne et al., 2005; Mullen, 1997). Concordance, in turn, recognises tailored and consensual therapeutic plans with a sufficient exchange of information and discussions to make informed decisions on what is best for the patients themselves, meeting their expectations and therefore leading to higher satisfaction and health outcomes (Mullen, 1997; Rao et al., 2000; Wittmann et al., 2011).

Some studies investigated the patient–HCPs concordance concerning information related to chronic conditions such as cancer and found a notable disagreement on important aspects related to oesophageal cancer (Andreassen, Bujnowska-Fedak, et al., 2007), prostate cancer (Ruesch et al., 2014) and prognostic information about chemotherapy for colorectal cancer (Elkin et al., 2007). There is however a current lack of studies that objectively measure patient–clinician concordance towards information needed on premalignant and cancer-linked conditions and specifically the OED. The recently developed and validated self-administered Oral Epithelial Dysplasia Informational Needs Questionnaire (ODIN-Q) to assess the information needs showed adequate reliability and validity in this specific cohort of patients (Alsoghier et al., 2020).

The present study describes secondary analyses of patient responses to ODIN-Q from the previous study and comparisons with those of clinicians who routinely involved in the clinical care of these patients. The present study aimed to answer (1) whether the patients' IN regarding OED were met, (2) what information is considered important by patients, (3) whether clinicians of different career grades and specialities allied to dentistry were able to predict the important information domains and topics to patients concerning OED and (4) what is the degree of patient–clinician, patient–patient and clinician–clinician agreements on the unmet/important information concerning OED.

2 | PATIENTS AND METHODS

2.1 | The patient's information needs study

This was a secondary analysis of the prospective and cross-sectional study to assess the IN of 86 patients who participated in the ODIN-Q study (Alsoghier et al., 2020) and to those of clinicians. Recruited patients were adults who received a histopathological diagnosis of OED per the 2017 WHO criteria (El-Naggar et al., 2017), aged 18 or above with good command (written and spoken) of English language and with no history of recent (over the past 5 years) or concurrent malignancy. Each participant has completed the 33 ODIN-Q items categorised under six domains (information about the disease, investigative tests, treatments, physical aspects, psychosocial aspects and medical system and access to information). Items were scored based on 4-tier for each amount of information received (too much

to none) and degree of importance subscales (very important to not at all). Ethical approval was obtained from the NHS Health Research Authority and Research Ethics Committees [18/LO/1340].

2.2 | The patient–clinician concordance study

Clinicians who routinely manage patients with OED in clinical care settings allied to dentistry were recruited using different approaches. These include a web-based version using a premium online survey software (https://www.surveymonkey.com) and a printed version to the members of national and international professional bodies allied to oral medicine (the British and Irish Society of Oral Medicine and the European Association of Oral Medicine). Both versions of the survey were anonymous and in line with the Data Protection Act 2018 (Health Research Authority, 2021).

In addition to the invitation letter, the study questionnaires included the demographics' form and the 33-item clinician's version of ODIN-Q, which only included the degree of importance scale (Alsoghier et al., 2020). As the clinicians' version of ODIN-Q was developed before the finalisation of ODIN-Q by patients, two items were not included in the concordance analysis (chances of a cure and the diet and nutrition).

2.3 | Data analysis and representation

The responses were presented in a Microsoft Excel (v 16.32) proforma with numerical representation and analysed by IBM SPSS statistical software (version 22.0). A pre-defined cut-off score for ODIN-Q was considered for the participant's sum score lies below the median of the total score of the recruited sample (Meesters et al., 2011). The normality of data distribution was tested by the Shapiro–Wilk test (Shapiro & Wilk, 1965), and Pearson's or Spearman's correlation coefficient (two-tailed test of significance) was used to measure correlations between the variables (Overholser & Sowinski, 2008). Values were interpreted based on Guilford's interpretation as low [0.20–0.40], moderate [0.40–0.70] or high [>0.70] (Guilford, 1950). Further analyses for association included the stepwise linear logistic (ordinal and binary) regression based on the type of outcome (Riffenburgh, 2012).
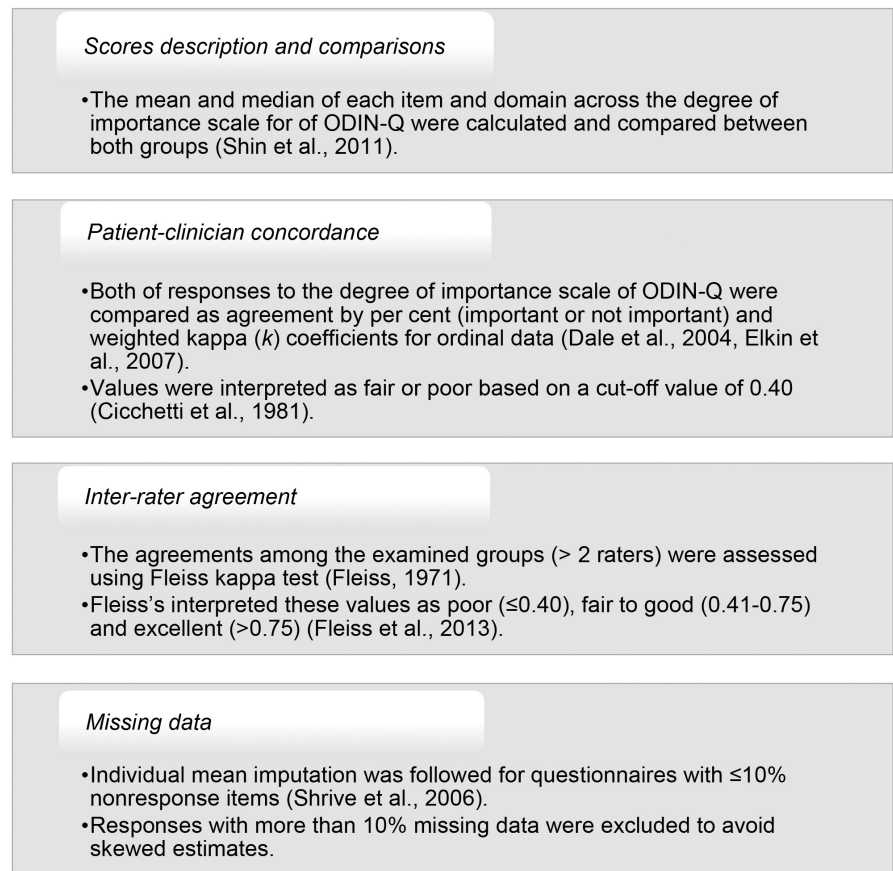
Unlike the other studies of concordance between patients and their clinicians (Ruesch et al., 2014; Shin et al., 2011), the invited clinicians were not involved in the care of the recruited patients with OED for proportionate comparisons. Therefore, methods from similar studies were employed (Figure 1).

3 | RESULTS

3.1 | The patient's information needs study

A summary of the characteristics for 86 recruited patients who presented with a mean and median age of 65 is shown in Table 1.

FIGURE 1 Summary of the study data analyses for concordance study.

> ### Scores description and comparisons
>
> - The mean and median of each item and domain across the degree of importance scale for of ODIN-Q were calculated and compared between both groups (Shin et al., 2011).

> ### Patient-clinician concordance
>
> - Both of responses to the degree of importance scale of ODIN-Q were compared as agreement by per cent (important or not important) and weighted kappa (*k*) coefficients for ordinal data (Dale et al., 2004, Elkin et al., 2007).
> - Values were interpreted as fair or poor based on a cut-off value of 0.40 (Cicchetti et al., 1981).

> ### Inter-rater agreement
>
> - The agreements among the examined groups (> 2 raters) were assessed using Fleiss kappa test (Fleiss, 1971).
> - Fleiss's interpreted these values as poor (≤0.40), fair to good (0.41-0.75) and excellent (>0.75) (Fleiss et al., 2013).

> ### Missing data
>
> - Individual mean imputation was followed for questionnaires with ≤10% nonresponse items (Shrive et al., 2006).
> - Responses with more than 10% missing data were excluded to avoid skewed estimates.

Furthermore, six participants (7%) had a history of malignancy, 63 of them (73%) had no symptoms related to the OED lesion and its associated clinical/histological diagnosis, and 20 (23%) had intermittent soreness/pain. The participants also had an average of three ongoing general medical conditions or issues (highest=9, lowest=0) and an average number of medications of 3.5 for each participant (highest=15, lowest=0). However, these findings might be carefully interpreted due to the influence of a clinician's style, reasons for the recent visits and the number of consultations conducted.

The analyses of participants' responses for each item under both scales of ODIN-Q are shown in File S1.

The mean and median total scores for all items in subscale 1 (amount of information received) were at 2.33 (±0.38) and 2.44, which indicated an overall unmet IN about OED among the present study sample for the six domains. Items under the medical system and access to information domain obtained the lowest mean and median scores (2.11/2.02) followed by psychosocial aspects of OED (2.27/2.25) and physical aspects of OED (2.30/2.27). In contrast, the highest-scored domains achieved scores marginally above the 50th percentile value of total score for all domains (2.44); information about treatments for OED (2.47/2.65), information about the disease (2.49/2.57) and information about investigative tests of OED (2.28/2.50).

Based on the analyses of mean scores for individual items (File S1), the 35 items were regarded as 10 highly unmet (29%), 14 somewhat met (40%) and 9 often met items (26%). In contrast, around 49% of the participants (*n*=42) had unmet IN concerning OED based on the cut-off level for subscale 1 (sample median=82).

For subscale 2 (degree of importance), 81 of the 86 participants (94%) viewed most of ODIN-Q items as important, with five respondents considered some or many items as unimportant. The highest important items for nearly all participants were about the fear of progression to cancer, disease grades and risk of developing mouth cancer, the screening and early detection and what will happen if it is not treated. By analysing both scales of ODIN-Q, 14 items were important and insufficiently addressed (Figure 2).

Moreover, 95% of the 86 participants opted for one or more choices as their preferred sources of information about OED. The highest selected choice was one-to-one meeting (76%) with OED specialists such as those in oral medicine, oral surgery or ENT specialities (*n*=53), general dental practitioner (*n*=32), general practitioner (*n*=27) and auxiliary medical staff such as medical or dental nurses (*n*=26). Furthermore, highly chosen sources included printed information materials such as pamphlets, books, magazines, newspapers (53%) and the Internet (35%). On the contrary, four participants did not indicate a preference for these sources.

The responses to the open-ended question at the end of ODIN-Q (*please indicate other topics not included in the list*) included suggestions for further topics to be considered or discussed with the clinical care team and personal experiences related to the disease or its management (Table 2).

As Shapiro–Wilk test indicated a non-normal distribution of ODIN-Q scores ($p < 0.05$); thus, Spearman's correlation coefficient indicated a negative correlation between the score of the amount of information received scale and both the number of current medical

TABLE 1 Demographics and clinical characteristics of the patients ($n = 86$).

Variable	Category	No. of participants (%)
Demographics		
Gender	Female	45 (52%)
	Male	41 (48%)
Age	50–69 years	49 (57%)
	70–89 years	30 (35%)
	30–49 years	6 (7%)
Ethnicity	White	67 (78%)
	Asian	16 (19%)
	Others	3 (3%)
Edu. level	Some college	22 (26%)
	Postgraduate degree	17 (20%)
	Bachelor's degree	16 (19%)
	Less than high school	14 (16%)
	High school diploma	12 (14%)
Employment status	Retired	51 (59%)
	Employed	27 (31%)
	Unemployed	4 (5%)
	Not disclosed	4 (5%)
Smoking	Current	9 (10%)
	Past	48 (56%)
	Never	29 (34%)
Drinking	Current	54 (63%)
	Never or rare consumption	25 (29%)
Clinical characteristics		
OED grade[a]	Low grade	90 (63%)
	High grade	53 (37%)
OED site[b]	Tongue	51 (46%)
	Of which involving the lateral sides	38 (34%)
	Buccal mucosa	21 (10%)
	Upper and lower gingiva	13 (12%)
	The hard and soft palate	12 (11%)
	Others	14 (13%)
Associated clinical/ histological diagnosis	Oral lichen planus	35 (40%)
	Not recorded	24 (23%)
	Oral leucoplakia	9 (10%)
	Oral candidiasis	8 (9%)
	Oral submucous fibrosis	3 (3%)
	HPV-associated (koilocytic)	2 (2%)
	Oral erythroplakia	1 (1%)
	Others[c]	3 (3%)

[a]The participants presented with 143 biopsy reports with an average number of 1.67 for each participant (highest per person = 13, lowest = 1).

[b]Of 111 affected sites of the oral cavity.

[c]Other conditions which may however not be necessarily related to oral epithelial dysplasia (OED) lesions (immunosuppression therapy, mucous membrane pemphigoid and dermatomyositis).

conditions ($r = -0.389$, $p = 0.000$) and the number of current medications ($r = -0.394$, $p = 0.000$). However, these were considered negligible based on Guilford's interpretation.

When the demographics and clinical variables were tested with regression models, the amount of information received score was significantly related to the number of medications ($p < 0.05$). As shown by the linear regression analyses, the score was decreased by 1.51 for every additional medication ($t = -0.326$, 95% CI [−2.46 to −0.55]). Whereas the category of amount of information received (met or unmet IN) was significantly predicted by the gender ($p < 0.05$) as found with the binary logistic regression (Wald test forward method). This test indicated that males were 65% less likely to report 'not enough' information about OED than females (OR = 0.35, 95% CI [0.14–0.86]) with a statistical significance level (p value) at 0.022.

3.2 | The patient–clinician concordance study

Seventy-seven clinicians completed the electronic ($n = 44$) and printed ($n = 34$) study questionnaires. Males represented 53% of those clinicians. As some participants had more than a speciality affiliation, all clinicians had oral medicine and oral surgery affiliations along with dental-allied specialities (e.g. special care dentistry, oral pathology, facial pain, oral radiology, epidemiology and restorative dentistry [$n = 1$ for each]). Clinicians had oral medicine's Master's ($n = 12$) and PhD degrees ($n = 29$), speciality training ($n = 32$), higher diploma ($n = 7$) or practising as general dentists ($n = 3$). They were also practising in 24 different countries located in five continents (Europe, North and South Americas, Asia and Australia) with the majority in the United Kingdom ($n = 22$), Sweden ($n = 12$) and Italy ($n = 10$).

Notably, patients provided higher importance scores to items on investigative tests, physical and psychosocial aspects domain and slightly similar scores on information about the disease, treatments and medical system and access to information domains to those indicated by clinicians (Figure 3 and Table 3).

Table 3 also shows the weighted k values of concordance between clinicians and patients with an overall average poor agreement of 0.06. Regarding the agreement between clinicians, Fleiss Kappa's coefficients showed very poor inter-rater agreements on the item level with an overall value at 0.090 (95% CI: 0.084–0.097 [$p < 0.05$]). Responses to the open question and comments from clinicians are shown in Table 4.

4 | DISCUSSION

To apparently address the information needs (IN) of a patient, it is necessary to consider three aspects; (a) why this information is being needed, (ii) what factors affecting the information needed (e.g. psychological, behavioural, self-efficacy, demographic, individualistic and environmental factors) and (iii) the situation when information is needed (Ormandy, 2011; Wilson, 1999). Therefore, clinicians need to

FIGURE 2 Important items viewed by the participants as insufficiently discussed ($n = 14$).
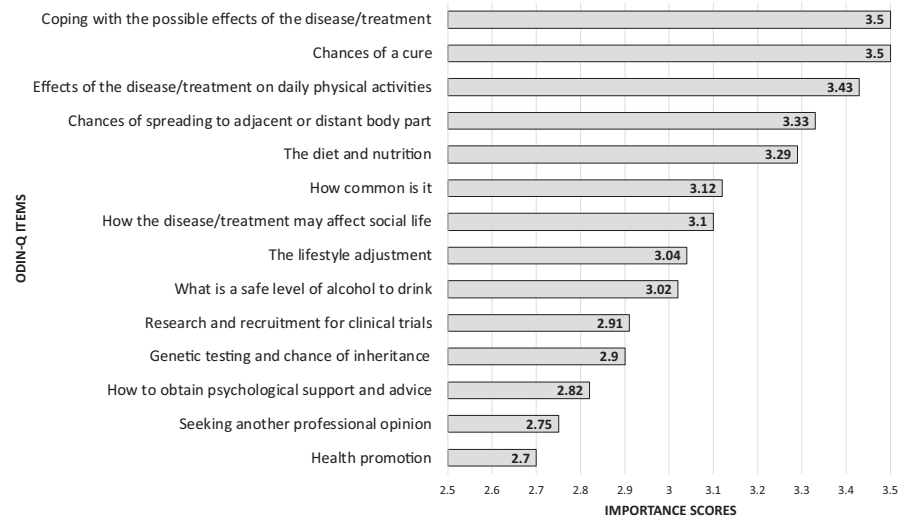
address these elements when using patient-reported measures, such as ODIN-Q, to evaluate the sufficiency and priorities of information and design interventions to deliver tailored and timely oriented information for patients with suspicious oral lesions (Chen et al., 2009).

The participated clinicians presently indicated low importance scores to the role of HPV due to perhaps the limited available evidence of the role of HPV or its high-risk subtypes upon OED development (Porter et al., 2018). This was reflected by 74% of patients who indicated 'none' or 'not enough' information received about this role. Studies on conditions possibly with a higher link to HPV than OED found similar findings with insufficient information often provided to patients about the role of HPV on head and neck cancer (O'Connor et al., 2020) and cervical conditions (Symmons et al., 2021). Nevertheless, it is notable that many analysed records of OED lesions in the present study were reported before 1996 when the term was described within the context of OED (Fornatora et al., 1996), attributed to a known history of oral potentially malignant disorders (OPMMDs) or high-risk factors (e.g. tobacco use). Thus, the information about the role of HPV might not have been sufficiently addressed during the consultations.

The high prevalence of reduced psychological well-being noted among patients with OPMDs (Tadakamadla et al., 2017) might cause many to perceive psychological support and advice as the second-highest unmet item in the present cohort. This finding was in line with a study on patients with OPMDs by Lin et al. (2015), who found increased unmet IN among patients with high state anxiety (Lin et al., 2015). Furthermore, the participants in the present study sought the importance of information about fear of progression to oral cancer, which can remain despite the reassurance during the consultation and the evidence showing that a few of these lesions will progress (Iocca et al., 2020). This fear was also an expected outcome of individuals after receiving the diagnosis of cancer-linked conditions such as abnormal cells in the cervix (Hellsten et al., 2009; Rask et al., 2017).

The present findings of domains of treatments, disease and investigative tests being important to patients were similar to those reported by patients with breast (Galloway et al., 1997) or prostate cancer (Galloway et al., 1997). Similarly, studies of cancer-linked lesions reported insufficient information receipt on aspects related to the access to information and investigative tests (Rask et al., 2017). Furthermore, individuals at high risk of OPMDs often have limited ability to seek and understand information needed for behavioural changes such as information about diet and nutrition (Lin et al., 2015), which was unmet among more than half of the participants presently.

The preferred sources to receive information about the disease were also similar to those found by a systematic review of studies investigating IN among patients with cancer, with the most common source being HCPs (mainly medical specialists [e.g. the oncologist]) and the printed information materials as the next (Constantinidou et al., 2009; Rutten et al., 2005). In contrast, all participants in one study considered the Internet as their primary source, some of them felt uncomfortable due to the nature of the information provided or they could not find answers to their concerns (Rask et al., 2017) which is likely to be similar as regarding OED and OPMDs (Alsoghier et al., 2018). The issues regarding the trustworthiness and credibility of health information are likely to be encountered too on the increasingly used social media platforms, which are often preferred and trusted by individuals with limited health literacy compared with those given by HCPs (Chen et al., 2018).

Regarding the patient–clinician agreement, clinicians predicted 7 of the 9 highest-scored aspects of information wished by patients. Nevertheless, they poorly estimated the degree of importance based on the 4-responses scale for all items with a k coefficient at 0.06. Similar findings were reported regarding the supportive cancer care needs in Korea by Shin et al. (2011), who noted weak patient–clinician agreements on supportive care needs with k coefficients between 0.04 and 0.15. Likewise, they noted a poor overall agreement of 0.16 on cancer-related information (Shin et al., 2011). Also, Elkin et al. (2007) found a further low degree of agreement on cancer information preferences of elderly patients and their physicians of −0.11.

TABLE 2 Participants' responses (patients) to the open question.

'Would be helpful to be able to share anecdotally treatment options, outcomes with similarly diagnosed patients' [White female, age 71, low-grade OED]

'Referrals from [named hospital, A] to [named hospital, B] not hearing the same message i.e. *[named hospital A] say urgent excision, [named hospital B] say non urgent'* [White female, age 61, high-grade OED]

'I feel I have been hooked after very well at all strives with treatment/ checks etc.' [White female, age 56, low-grade OED]

'Recovery/healing post surgery information, how many stitches, how long before they disappear, pain/duration and severity after surgery, and advice on suitable diet' [White female, age 68, low-grade OED]

'Would photo's/illustrations improve understanding of OED and did information about OED derive mainly from (a) written material given to you; (b) internet search; or (c) what you were told by medical staff at the clinic' [White male, age 70, low-grade OED]

'Many of the questions not applicable in my case, as my problem remained dormant since being diagnosed and therefore discussion of treatment is unnecessary. My periodic visits are essential for my own assurance' [White male, age 75, low-grade OED]

'Essentially I was told there was no definitive cause + no definitive treatment or prognosis. The OED might disappear as mysteriously as it came, or it might become cancerous. It should be kept much frequent regular observations + if it shows signs of getting worse, the only option was surgical excision. When it gets worse, I was warned that my tongue might permanently lose feelings + the OED might return–neither has happened (yet!)' [White male, age 71, high-grade OED]

'(1) none of the medical staff have explained the definition of these words; (2) I am told about the importance of regular monitoring, but never any detail of why or how it may differ for each individual; (3) I have some general knowledge of most of these topics, but none or very little received or offered; (4) these words (what OED is) have never been explained to me; (5) I apply common sense and eat sensitively (about the diet and nutrition) as well as the other items of ODIN-Q.

For nearly all of these questions + topics, I have quietly considered them over the years since starting at [named hospital], but never raised any of them explicitly with the doctors I have seen'. [White male, age 68, low-grade OED]

If it is not unexpected that there will be some discordance between what information patients wish and what clinicians can provide—or think relevant. This gap would need to be reduced to maintain primary prevention of oral cancer by adopting healthy behaviour changes such as tobacco use cessation, reducing alcohol consumption and modifying the dietary pattern to reduce the molecular events leading to carcinogenesis of the mouth (Meurman, 2010; Touger-Decker et al., 2014). Notably, 89% of patients noted the importance of dietary advice with 57% indicating unmet IN towards it. There is however a lack of specific and evidence-based guidelines towards the lifestyle factors with relevance to the malignant potential of OED (e.g. alcohol consumption). What is the safe/recommended level of alcohol to drink for individuals specifically for oral cancer is yet to be determined as the available guidance is related to general health rather than oral health (UK Department of Health, 2016) or cancer prevention in general (Kushi et al., 2012).

Challenges arise upon ensuring a tailored exchange of information during the sometimes-limited time frame for a clinical visit (Freeman et al., 2002; Mira et al., 2010). For instance, a patient could be simply asked, 'tell me what you know about your diagnosis' and whether they know specific information about their diagnosis that might not be easy to comprehend (Bultz & Butow, 2011), such as 'dysplasia', 'biopsy', 'risk of mouth cancer' or their clinical and/or histopathological diagnosis with OPMDs such as 'oral lichen planus'. The main topics for discussion need to be previewed first, summarised and then linked to the subsequent agreed actions to improve understanding and retention (Bultz & Butow, 2011). Also, supporting individuals who had a high risk of oral cancer with an information leaflet could contribute to better symptoms appraisal, higher ability to perform mouth self-examination and higher confidence to seek professional help for worrying symptoms (Lee et al., 2019). If these steps help address the patient's concerns and obtain their satisfaction in fewer visits, it can result in better healthcare utilisation and correspondingly reduced expenditure (Schumacher et al., 2013).

The present study used a specific and validated questionnaire to assess IN concerning OED. In addition, the sample size of 86 patients and 77 clinicians are considerably high for a disorder with a
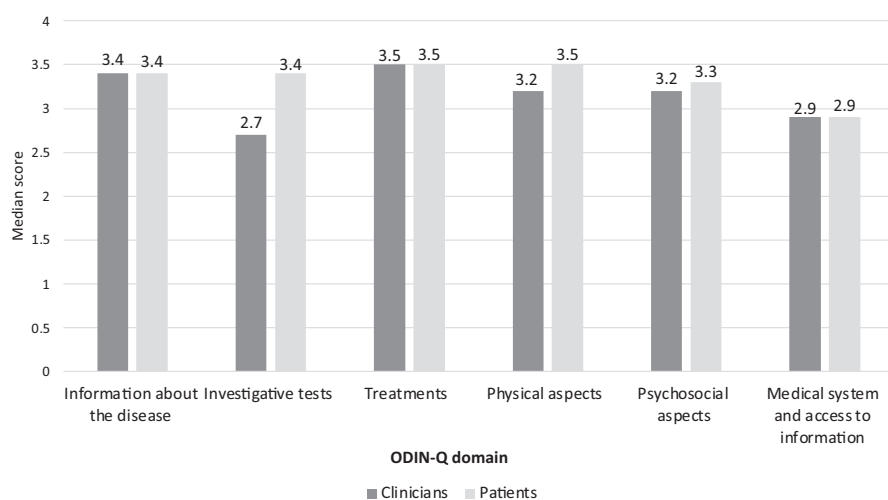

FIGURE 3 Importance ratings of each domain of Oral Epithelial Dysplasia Informational Needs Questionnaire (ODIN-Q) by clinicians and patients.

TABLE 3 Patients' and clinicians' ratings and concordance on ODIN-Q items (n = 33).

Domain	ODIN-Q item	Median (mean) importance score		Concordance[a]	Percentage of patients/ clinicians	
		Patients	Clinicians	Weighted k coefficient	Important	Not important
Information about the disease	What OED is?	3.59 (3.55)	3.75 (3.7)	0.050	95/95	5/5
	How common is it?	3.22 (3.12)	3 (2.98)	0.056	84/74	16/26
	Risk factors for developing OED	3.47 (3.38)	3.72 (3.7)	0.049	87/97	13/3
	How it looks in the mouth or lips?	3.48 (3.43)	3.28 (3.24)	0.244	93/13	7/87
	Whether it is contagious or not?	3.44 (3.39)	3.05 (2.98)	0.095	94/74	6/26
	The role of HPV	3.03 (2.91)	2.66 (2.67)	0.028	74 /58	26/42
	Disease grades and the risk of developing mouth cancer	3,71 (3.65)	3.78 (3.76)	−0.144	96/97	3/3
	What will happen if continues to smoke or drink alcohol?	3.39 (3.26)	3.74 (3.71)	−0.006	84/95	16/5
	What is a safe level of alcohol to drink?	3.14 (3.02)	3 (2.97)	−0.015	76/74	24/26
	What is likely to happen to OED in the future?	3.58 (3.53)	3.67 (3.73)	−0.069	94/95	6/5
Investigative tests	The screening and early detection	3.67 (3.62)	3.61 (3.57)	0.138	94/95	6/5
	The genetic testing and chance of inheritance to children[b]	3.11 (2.90)	2.26 (2.98)	−0.022	72/36	28/64
	Benefits, risks, how each test works, and the meaning of test results	3.46 (3.40)	2.79 (2.81)	0.114	89/63	10/37
Treatments	What will happen if it is not treated?	3.63 (3.60)	3.72 (3.71)	−0.06	95/99	5/1
	Treatment options, benefits, risks and how each treatment works	3.61 (3.58)	3.67 (3.66)	0.056	94/99	6/1
	How the disease/treatment affects the quality of life	3.51 (3.45)	3.52 (3.49)	−0.007	91/94	9/6
	Self-management at home	3.5 (3.45)	3.28 (3.22)	0.079	93/77	7/23
	Complementary and alternative medicine	2.64 (2.60)	2.25 (2.28)	−0.054	58/32	49/68
Physical aspects	How frequent and severe are the symptoms?	3.58 (3.50)	3.27 (3.23)	−0.05	95/86	5/14
	Chances of spreading to an adjacent or distant body part	3.42 (3.33)	3.03 (2.93)	0.050	89/76	10/24
	How the disease/treatment affects daily physical activities	3.50 (3.43)	3.23 (3.18)	0.026	92/87	8/13
	Fear of progression to cancer	3.71 (3.29)	3.78 (3.75)	−0.040	98/96	2/4
Psychosocial aspects	Coping with the possible effects of the disease/ treatment	3.55 (3.50)	3.35 (3.33)	−0.091	93/95	7/5
	How the disease/treatment affects social life	3.20 (3.10)	3.12 (3.07)	−0.074	78/74	22/26
	How the disease/treatment affects job/career[b]	2.75 (2.70)	2.9 (2.92)	−0.023	63/70	37/29
	The experience of the doctor and other healthcare staff	3.46 (3.40)	3.15 (3.12)	−0.024	93/83	7/17
Medical system and access to information	Seeking another professional opinion	2.83 (2.75)	2.73 (2.74)	0.002	63/68	37/31
	Physical support and advice	3.51 (3.44)	3.44 (3.4)	−0.013	91/91	9/9
	Psychological support and advice	2.89 (2.82)	2.90 (2.87)	0.033	64/73	35/27
	Community/patient support groups	2.06 (2.18)	2.56 (2.57)	−0.033	35/53	65/47
	Health promotion (e.g. promoting one's health literacy)	2.75 (2.70)	3 (2.94)	−0.099	63/73	37/27
	The lifestyle adjustment	3.2 (3.04)	3.59 (3.54)	−0.026	78/91	22/9
	Research and recruitment for clinical trials	3 (2.91)	2.58 (2.59)	0.045	71/51	29/9

[a]Concordance refers to the patient–clinician agreement based on the 4-tier importance scale (very important, important, not important and not at all important).

[b]Deleted items from the final ODIN-Q (v 2.0).

TABLE 4 Participants' responses (clinicians) to the open question.

'In my opinion, it is not absolutely important to give too many information to the patient. It's enough for him [the patient] to know only basic, clear information and the periodic control'
'Most seem important'
'Interesting range of questions'
'All of the above would be of interest to a patient diagnosed with OED'
'Government guidance on weekly alcohol consumption relates to general health and not specifically development of oral cancer/PMLs'
'Please forgive me but I do not agree with the term OED. OED is not a clinical term and not easily understandable among patients. I would prefer to use for my patient "Oral lesions with risk of malignancy"'
'I believe that raising awareness among general dental practitioners to refer the patient with OED to a hospital setup and mark the referral urgent. Investing in research and RCT is crucial'

low incidence rate as well as this of questionnaire-based concordance studies on IN between oesophageal cancer patients ($n=15$) and HCPs ($n=34$) (Andreassen, Randers, et al., 2007) as well as the desire for information among elderly cancer patients ($n=73$) and oncologists ($n=19$) (Elkin et al., 2007).

However, the study is presented with some limitations, such as assessing the concordance between patients and not-treating clinicians. Therefore, it was not possible to determine the predictors for high or low concordance related to patients (e.g. demographics including the age, gender and socioeconomic status; Ancel, 2012; Shin et al., 2011) or their disease (e.g. time since being diagnosed; Ancel, 2012, severity; Perrin et al., 2000 and associated extra-oral manifestations; Carrozzo et al., 2019), and clinicians (e.g. length of experience; Shin et al., 2011). Moreover, the present study did not assess patient satisfaction or trust in clinicians and its relevance to the concordance with their clinicians (Shin et al., 2011). Perhaps a subsequent longitudinal assessment would be feasible to see whether individuals of high agreement with their clinicians would encounter favourable health outcomes than those of low or neutral agreement (e.g. lower rates of developing new lesions or malignant transformation).

5 | CONCLUSION

The present study has found that 49% of patients had unmet IN about OED. Although patients provided higher importance scores than clinicians, the latter were generally able to predict the highest important topics to patients, but they inadequately predicted its importance. This should encourage clinicians to assess the patient's IN, possibly with qualitative research or instruments such as ODIN-Q, for tailored and patient-centred information exchange during consultations to support making informed decisions. Future research may consider assessing this agreement with the treating clinicians to examine predictors of high or low agreement related to the patients, their disease and those of consultations.

CONFLICT OF INTEREST STATEMENT

The authors declare that they have no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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