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► To cite this version:

Jerry Tan, Stefan Beissert, Fran Cook-Bolden, Rajeev Chavda, Julie Harper, et al.. Evaluation of Psychological Wellbeing and Social Impact of Combined Facial and Truncal Acne: a Multi-national, Mixed-Methods Study. *Dermatology and Therapy*, 2022, Online ahead of print. 10.1007/s13555-022-00768-0 . inserm-03741269

HAL Id: inserm-03741269

<https://www.hal.inserm.fr/inserm-03741269>

Submitted on 1 Aug 2022

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Evaluation of Psychological Wellbeing and Social Impact of Combined Facial and Truncal Acne: a Multi-national, Mixed-Methods Study

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Received: March 11, 2022 / Accepted: June 27, 2022
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ABSTRACT

Introduction: Half of the individuals with facial acne develop truncal acne, but the impact of combined facial and truncal acne (CA) on patients' quality of life is poorly researched.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s13555-022-00768-0>.

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Methods: A 60-min interview of 30 participants with CA was conducted that formed the basis for a cross-sectional survey of 694 adolescents and adults with CA.

Results: The main themes identified from the qualitative interviews among CA subjects included acceptability to self and others, social functioning and emotional wellbeing. Feelings of embarrassment, self-consciousness and low confidence were experienced often or all the time by over 50% of participants, and were

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more frequent in those who perceived their acne to be out of control ($P = 0.003$). Half of patients reported feeling stigmatised because of their CA, and 65.4% believed that others associated their truncal acne with unhealthy or unhygienic habits. Perceived stigma was associated with more feelings of embarrassment ($P = 0.005$), self-consciousness ($P = 0.034$) and low self-confidence ($P = 0.017$). Overall, 64% participants reported that CA interfered with daily life, 46.4% often or always avoided social interaction, 48.6% were often concerned about talking to unfamiliar people and 47.4% were uncomfortable showing affection. Further, 32% and 24.4% participants ≥ 16 years old avoided dating or having romantic/intimate relationships because of their facial and truncal acne, respectively. Social and leisure activities were more frequently negatively impacted among those with perceived uncontrolled CA than among those with controlled CA. Avoiding undressing in front of spouse/partner/friends/relatives was more commonly reported by participants with perceived uncontrolled truncal acne than by those with controlled truncal acne (90.5% versus 80.6%, $P = 0.031$).

Conclusion: CA is associated with considerable psychological morbidity, with several exacerbating (e.g. perceived stigma) and attenuating factors (e.g. acne being perceived as being under control) that should be accounted for in CA management.

Keywords: Facial acne; Mixed method; Qualitative survey; Quality of life; Quantitative survey; Truncal acne

Key summary points

Combined facial and truncal acne (CA) had significant psychosocial impact in the form of embarrassment and self-consciousness.

Subjects with CA felt significantly stigmatised, i.e. judged, for their acne and felt as if people were staring at their acne often or all the time, and the perceived stigma was associated with more feelings of embarrassment, self-consciousness and low self-confidence.

Acne appearance-related concerns, stigma and/or daily life restrictions negatively affected social activities and personal relationships.

Individuals who perceived that their CA was uncontrolled expressed significantly higher impact on quality of life (QoL).

INTRODUCTION

Acne is a common condition affecting most teenagers and may persist into adulthood [1–3]. Acne has the potential to adversely impact health-related quality of life (HRQOL) [4–8]. Acne scarring, a sequela of acne, may further exacerbate negative psychosocial aspects [9]. The psychological and social disability due to acne is similar to that in other chronic medical conditions such as asthma and diabetes [10].

Studies focussed on patient-reported outcomes (PROs), including symptom severity and impact on HRQOL, are key components of effective, patient-centred services aimed at capturing and meaningfully incorporating the patient's experiences, perspectives, needs and priorities into clinical practice and drug development. Accordingly, many studies have explored the impact of acne on psychological and social wellbeing, but these have focussed mainly on facial acne using dermatology-specific HRQOL measures [11–13]. While the results from these studies may be relevant for facial

acne, half of these patients also have truncal acne (i.e. combined facial and truncal acne; CA) [14, 15]. Most existing HRQOL instruments have not been validated for acne on areas other than the face and may, therefore, not truly encompass the impact of truncal acne.

Here, we present results from a mixed methods approach aimed at describing the key aspects of the experience, perception and attitude of patients living with CA. An explanatory sequential design was used where, first, qualitative exploratory data were collected and the findings were used to develop a quantitative survey adapted to the sample under study. Recently developed patient's self-completion instruments that specifically address CA evaluation were also incorporated into the cross-sectional survey. The qualitative data were further used to provide context to numerical values derived from the quantitative survey to enhance the relevance of findings.

METHODS

This mixed-methods study was conducted sequentially, with the qualitative part run prior the quantitative one, to design the quantitative questionnaire based on the qualitative findings. These were conducted and administered in the native language of each country (i.e. USA, Canada, Brazil, France, Italy, Germany). Linguistic translation into each country's local language was conducted in accordance with conventional methodology (back-translation by TransPerfect, October 2019).

The research complied with General Data Protection Regulation (GDPR), all international/local data protection legislation and Insights Association/European Society for Opinion and Marketing Research (ESOMAR)/European Pharmaceutical Market Research Association (EphMRA)/British Healthcare Business Intelligence Association (BHBI). All adult subjects provided informed consent prior to participation. Legal guardians gave consent for individuals who were younger than 18 years. Assent from paediatric participants was also obtained. The study received a favourable opinion by the Kantar Internal IRB/

Ethics Committee and was performed in accordance with the Helsinki Declaration of 1964 and its later amendments. Study design, data collection, data management and analyses were conducted by Kantar Health (France).

Participants for the qualitative and quantitative studies were between 13 and 40 years who received a diagnosis of acne by a physician and were currently being followed by a healthcare professional (HCP) and receiving prescription treatment for acne. Acne diagnosis was self-reported, and the severity was assessed using a self-rated six-category pictorial global acne grading system based on the Investigator Global Assessment (IGA) for the face, which was modified to include the trunk (chest, back, shoulders) [16]. Information on clinical characteristics was collected to help validate the self-reported diagnosis of acne (e.g. family history of acne, presence of acne signs/symptoms, the number of years afflicted with the condition, body location, self-assessed severity of acne, acne treatments, and appointments with a dermatologist).

Qualitative Survey Procedures

Data collection: Thirty participants with CA were recruited by phone following a purposeful sampling strategy in 2019 for a 60-min telephonic semi-structured interview conducted by qualitative researchers as previously described and focussing on the psychological burden of CA and impact on the QoL as previously described [17].

Data analysis and interpretation: Qualitative data were descriptively analysed using audio records and a content-analysis grid. Data were organised by themes in a content analysis format. Analyses aimed at identifying emerging themes related to the overall QoL were based on the grounded theory method. Data were coded in terms of basic psycho-social processes, on the basis of how participants acted in response to different contexts. The first level of analysis was done locally by the local qualitative analyst, based on a content-analysis template to ensure homogeneity of the summarised findings. At the global level of analysis, two independent

coordinating qualitative researchers integrated the local analysis with a focus on identifying and describing country-specific similarities and differences in responses. Validation of findings included a craftsman approach that incorporates continually checking, questioning and theoretically interpreting findings. The voices of participants were emphasised through verbatim quotes reported with the unfiltered wording of the participants. The study was designed and conducted in accordance with the consolidated criteria for reporting qualitative research (COREQ) requirements [18] (Supplementary Material).

Quantitative Survey Procedures

Data collection: A cross-sectional, quantitative survey of an online respondent panel (i.e. Kantar LightSpeed GMI, Dynata, Toluna, M3, Lucid, BA) was conducted in 2019–2020 that included 694 participants with CA. The survey was developed following insights from the qualitative study (i.e. exploratory sequential design) [19]. Face and content validity of the survey was established by clinical experts (J.T. and B.D.). Photographs with examples of acne (e.g. comedones, papules, pustules and nodules) were provided to assist with self-recognition. The following validated HRQOL scales were administered: the dermatology life quality index (DLQI) (for participants ≥ 16 years), children's DLQI (CDLQI) (< 16 years) [20] and the Comprehensive Acne Quality of Life (CompAQ) (all ages) [21] referenced to the preceding week according to developer instructions.

Data analysis and interpretation: A quota sampling method based on geographical location was used to ensure that the sample of respondents was representative of the acne populations in study countries. An age, sex and country weighting adjustment was applied (Supplementary Material). Country was modelled as the primary sampling unit to account for clustering of data at the country level. Continuous variables were analysed using the Student's *t*-test or with analysis of variance (ANOVA) and expressed as mean and standard error of the mean (SEM). Categorical variables

were analysed by the chi-square independence test and expressed as frequencies. All tests were two-tailed, and a value of $P < 0.05$ was considered statistically significant.

RESULTS

Sample Demographics and Clinical Characteristics

Qualitative Interviews

Thirty participants (5 per study country) were recruited for qualitative interviews; 21 (70%) were 18 years and older (median age 23 years; range 13–37 years) and 17 (56.7%) were female (33% and 66.7% female among children (< 18 years) and adults (≥ 18 years), respectively). At the time of interview, 13 had acne on the face and back, 5 on the face and chest, 8 on the face, back and chest, and 4 on the face and neck/shoulders. All rated their facial and truncal acne as at least moderate. Ten had sought medical attention for acne within a month of the interview, 2 in the past 6 months and 10 within the past year. They were all on prescribed treatment for their acne.

Quantitative Survey

In total, 694 subjects with facial and truncal acne participated in the quantitative survey; 452 (65.2%) subjects were 13–17 years old, of which 162 (35.8%) were female; 242 (34.8%) subjects were 18–40 years old (60.9% female) (Supplementary Table 1). All subjects had been diagnosed with acne, mostly by a dermatologist or a paediatrician, at a mean age of 13.7 (0.14) years. The majority (67.1%) sought medical attention for acne in the first 3 months from the onset and 12.2%, 9.7% and 10.8% sought medical attention within 3–6 months, 6–12 months and after 1 year from symptom appearance, respectively. The study population had different severity levels of facial and truncal acne (Supplementary Fig. 1). The time from onset of facial and truncal acne ranged from a few months to 29 years [mean (SEM) durations of facial and

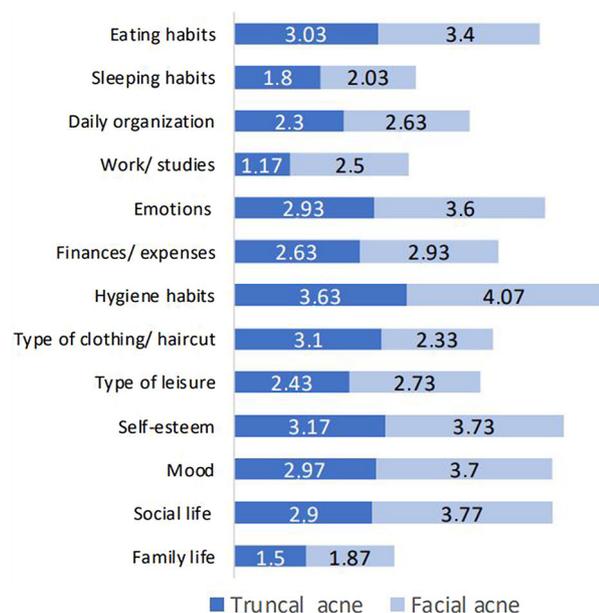


Fig. 1 Domains affected by acne burden in the qualitative survey. Self-completion ranking exercise on a five-point Likert scale where 1 means acne is ‘not at all impacting’ and 5 means ‘extremely impacting’ prior to qualitative interview. Truncal and facial acne were to be differentiated. $n = 30$

truncal acne were 6.1 (0.6) and 5.6 (0.5) years, respectively]. Late-onset facial acne (i.e. acne that begins after the age of 25 years) and truncal acne were reported in 2 (0.3%) and 4 (0.6%) women, respectively.

Central Themes

Appearance and Emotional Wellbeing

In qualitative interviews, recurrent themes of highest frequency related to the psychological consequences of CA were reduced self-esteem, poor self-image, self-consciousness and embarrassment (Fig. 1). Terms such as ashamed, looking dirty, unattractive, self-confidence and abnormal were commonly used during the interviews.

17 years old, male, Brazil: “My problem was my appearance; I started to feel ugly. It soon became a very constant and ugly thing, and it was getting worse over time.”

16 years old, female, France: “It soon became something I was ashamed of; one wonders what people will think. Looking into the mirror, I see that it becomes an obsession.”

36 years old; female; Brazil: “Horrible, because it appeared in places where [acne] should not exist.”

36 years old; female; Italy: “Because I feel estranged with myself, how could I feel comfortable with other people? Even if I’m better, there is always 10% of insecurity.”

Quantitative survey participants also stressed the importance of impaired self-esteem and self-image associated with psychological morbidity in CA. While 48.6% reported frequent pain or physical discomfort due to CA, the feelings of being embarrassed and unattractive were among the most common emotions associated with CA (Fig. 2).

17 years old; male; Brazil: “My problem was my appearance; I started to feel ugly.”

In total, 51.6% and 53.8% of participants in the quantitative survey often or always felt embarrassed and self-conscious because of their acne, respectively, and 53.5% often or always experienced decreased self-confidence.

15 years old; female; France: “Having acne on my upper back and chest can give me an inferiority complex when I am with friends who don’t have acne.”

Most quantitative survey participants (64.7%) who never consulted a physician for their truncal acne (9.1%) reported feeling embarrassed to address these concerns to physicians.

16 years old; female; France: “At the first [appointment] I felt intimidated to show all the acne areas on my body, but it went just fine.”

Acceptability to self and others

Both qualitative and quantitative data suggested a link between embarrassment, self-consciousness and fear of being judged/scrutinised by others. The theme of stigmatisation was

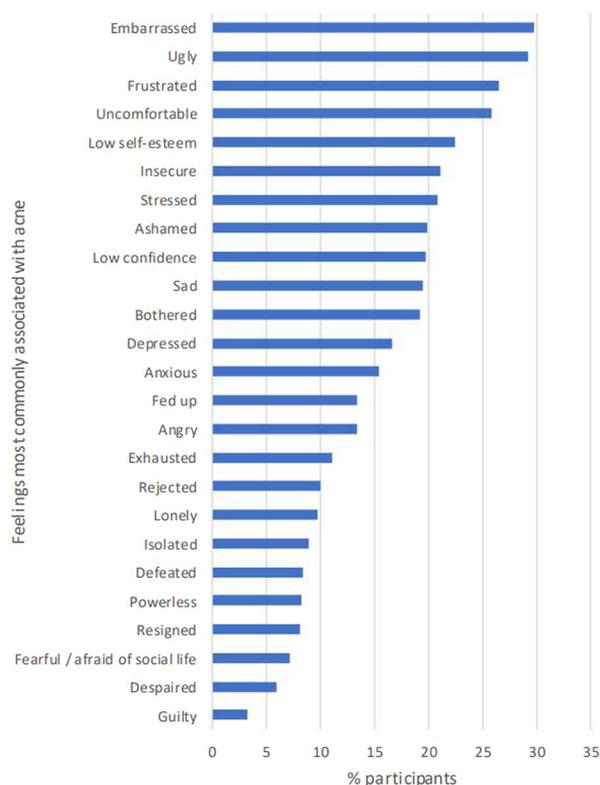


Fig. 2 Most common feelings associated with acne in the quantitative survey

recurrent, with the use of terms such as external judgement being recurrent during interviews. In agreement with this qualitative finding, half of the participants from the quantitative survey reported being stigmatised (judged for their acne and as though people were staring at their acne often or all the time).

36 years old; female; Italy: "If there is a business event, I always hope it takes place in the evening – acne is less visible when you are not in broad daylight."

31 years old; female; USA: "I won't go to the beach or the pool with friends. I won't wear sundresses in the summer. People have noticed the acne on my back, and I don't feel comfortable. It's frustrating and it hits my self-esteem."

36 years old; female; Italy: "In the summer period having acne also on my shoulder and on my back became a big issue. I'm used to go to the beach early in the

morning, sunbathing when there's few people. When I'm enough tanned and my acne is less visible, I can go to the beach also later, when there are people around."

In the quantitative survey, the more frequently participants felt they were judged, the more likely they were to report embarrassment ($P = 0.001$), self-consciousness ($P = 0.001$) and low self-confidence ($P = 0.001$). Overall, 40.5% of participants always or often felt that people thought less of them because of their acne and 41.3% felt that people treated them differently because of acne. In addition, 65.4% participants believed others blamed them for their truncal acne and associated it with unhealthy or unhygienic habits.

36 years old; female; Brazil: "Having acne in other places that not the face, is terrible, because people have the impression that we do not treat ourselves and do nothing about it. It hurts a lot!"

36 years old; female; Brazil: "When they see the acne in other parts of our body, they tend to think something like that: 'Look, what a bizarre thing!'"

Being taunted or teased was identified by the participants as a considerable problem: 61.9% reported experiencing negative comments of others regarding their skin and 58.6% indicated verbal and/or physical abuse because of their acne. Participants who reported bullying more often felt embarrassed ($P = 0.005$) as well as self-conscious ($P = 0.034$) and had low self-confidence ($P = 0.017$) than those who did not reported bullying.

19 years old; male; France: "My friends made fun of people who had a lot of pimples..."

Sociability and personal relationships

The theme "hide/type of clothing/haircut" was frequently encountered in the qualitative survey (Fig. 1). Similarly, in the quantitative survey, participants who often felt embarrassed about their acne were more concerned about hiding acne with clothes, hairstyles and makeup (Fig. 3a, b).

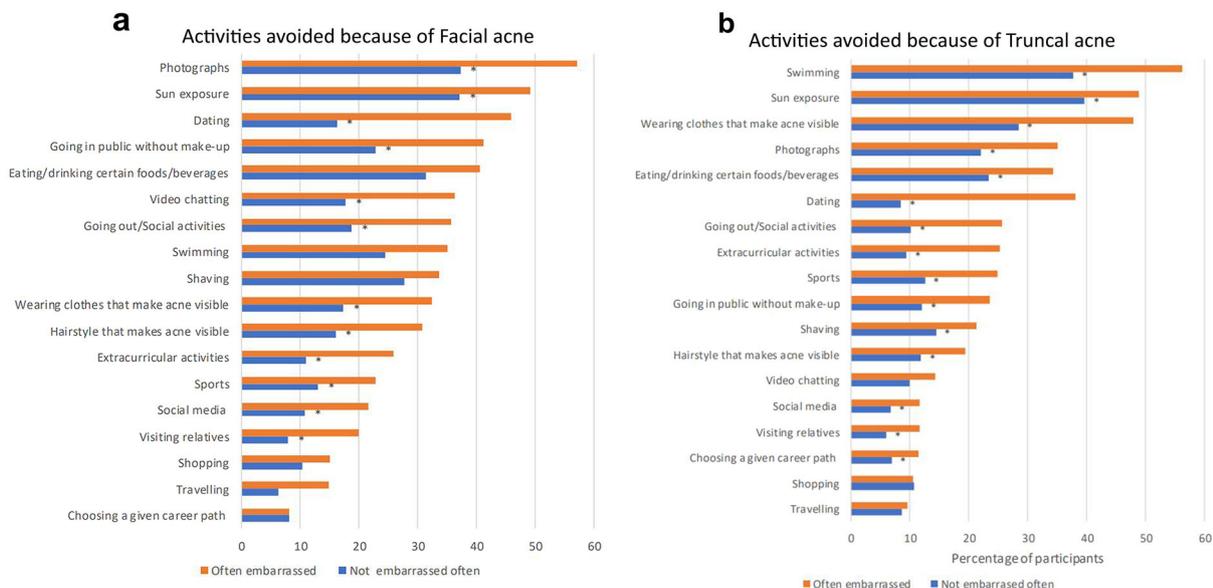


Fig. 3 a Percentage of participants from the quantitative survey who reported avoiding daily life activities because of the feeling of embarrassment from facial acne. Black dots indicate P value < 0.05 . **b** Percentage of participants from

the quantitative survey who reported avoiding daily life activities because of the feeling of embarrassment from truncal acne. Dots indicate P values < 0.05

31 years old; female; USA: “The acne on my back is worse but it is easily covered.”

13 years old; female; Germany: “The facial acne has a bigger impact, because on the shoulders and the neckline I can hide it.”

The central role of appearance-related concerns in embarrassment and impaired self-confidence became evident as participants reported avoiding situations where they saw themselves as being more exposed (e.g. photographs, at parties, changing rooms, swimming pool/beach). All participants from the qualitative survey recalled at least one situation where their acne had a direct impact on a social situation, i.e. they had turned down a party or gathering invitation because of their acne or a sudden flare up.

31 years old; female; USA: “I wanted to go to the beach with my co-worker, but I didn’t go because of my acne. I was annoyed that it could influence my decision.”

36 years old; female; Canada: “I’m not as willing to expose my back, because I don’t

have perfect skin, especially during flare ups.”

16 years old; female; France: “I had 2 weddings recently, it was difficult to get dressed. What I have learned the hard way that it wasn’t the best idea to wear a dress with an exposed back so now I try to avoid those types of events!”.

Overall, as reported by participants, acne appearance-related concerns, stigma and/or daily life restrictions negatively affected their personal relationships; 46.4% often or always avoided social interaction, 48.6% were often concerned about talking to unfamiliar people and 47.4% were uncomfortable showing affection to others. In total, 32.0% and 24.4% participants ≥ 16 years reported avoiding dating or having romantic/intimate relationships because of their facial and truncal acne, respectively. These percentages increased in those with feeling of embarrassment (Fig. 3a, b).

25 years old; female; Italy: “In general, facial acne impacts more on my daily life, on my social relationship. Actually, in this summer period, acne on the shoulders is

also really important. The shoulders acne is more visible.”

37 years old; male; USA: “It’s hard to meet new people. I don’t want them to see me like this.”

31 years old; male; Germany: “It has an impact on one’s sexual life, because you are completely naked in a real and in a metaphorical sense; I mean, you have to show yourself as you are; that costs a lot of effort.”

25 years old; female; Canada: “Because I’m so self-conscious I don’t get into relationships with men. I’m hesitant to meet new people or go out with friends without all my makeup.”

Daily Life and Leisure Activities

Participants from the quantitative survey reported adapting daily and leisure activities to address risk factors for acne [e.g. avoid eating or drinking certain foods/beverages (36.2% and 29.1% due to facial and truncal acne only, respectively) and sun exposure (facial, 43.5%; truncal, 44.4%)].

In total, 64.1% participants reported that CA interfered with daily life, owing to the time-consuming aspect of their acne care routine. On average, participants spent 17.9 (SEM 1.10) and 15.4 (0.85) min each day on care for facial and truncal acne, respectively.

23 years old; female; Brazil: “Having acne is having to have different eating habits than other people, with many restrictions, having to wake up too early to spend almost an hour in front of the mirror cleaning and passing creams, it is very tiring.”

The complexity of their acne care routine increased with an increase in acne severity of the face ($P = 0.053$), chest ($P = 0.039$) and back ($P = 0.001$).

22 years old; female; Brazil: “I pay more attention to my back, parts are difficult to apply; I’m quite stiff, reaching middle of my back, is difficult. It takes me more time to take care of my back than my face.”

Emotional Wellbeing and Daily Life Activities in Subjects with Controlled versus Uncontrolled Acne

Participants from the quantitative survey whose acne was perceived as being partially (facial, 65.2%; truncal, 66.8%) or completely (facial, 21.5%; truncal, 21.2%) under control (i.e. benefitted from treatment) reported fewer emotional issues associated with acne. Embarrassment was often/always experienced by 48.6% participants whose facial acne was under control versus 71.0% of those with uncontrolled facial acne ($P = 0.004$). Similarly, 48.7% and 72.8% participants with controlled and uncontrolled truncal acne, respectively, often/always had the feeling of embarrassment ($P = 0.003$). Similar statistically significant trends were observed for self-consciousness and low self-confidence (data not shown). Social and leisure activities were frequently negatively impacted in those with uncontrolled CA as compared with those with controlled CA. Participants with uncontrolled truncal acne reported more often avoiding undressing in front of spouse/partner/friends/relatives than those with controlled truncal acne (90.5% versus 80.6%, $P = 0.031$).

DISCUSSION

Our results indicate that CA has a negative impact on several domains of QoL, namely emotional wellbeing, acceptability to self and others, and social functioning. Feeling embarrassed and unattractive were among the most common emotions associated with CA. Although participants believed that the appearance of their acne had a negative impact on their attractiveness and self-esteem, they also felt being stigmatised for having acne. For instance, some subjects feared being blamed for their truncal acne (i.e. being thought unhealthy or unhygienic). The perception of being judged by others is supported by reports that people with acne are perceived as not meeting societal expectations [22]. These results are in line with those from previous studies showing that feelings of stigmatisation are common among patients with acne, psoriasis and atopic eczema

and that this is related to QoL impairment [23–25]. This negative perception of acne in society imposes a burden on those with acne as a reinforcing negative factor.

While the face is the most visible area in human interaction, we note that the addition of truncal acne, despite decreased daily visibility, conferred greater psychological impairment. In agreement with a previous report [26], here we found that truncal acne was particularly associated with feelings of concern about sexual and bodily appearance/attractiveness.

CA reduced self-confidence and instilled the fear of being exposed, leading to avoidance behaviour reported by study participants. These results are supported by the literature where social avoidance has been linked to poor self-image and self-esteem among subjects with skin disease [27, 28]. Furthermore, we observed that camouflaging CA with makeup, hair styles or clothes was a common adaptation to decrease embarrassment and self-consciousness.

Participants in whom acne was self-perceived as being under control reported fewer psychological sequelae and less negative impact on their daily activities. This observation is congruent with previous studies highlighting the benefit of effective acne treatments on QoL [29].

Individuals self-rating their acne as severe showed the highest psychological impairment according to validated HRQOL scales, which reinforces the existing data of increased perceived acne severity to decreased HRQOL [30]. As the impact of acne on HRQOL is influenced by its severity as perceived by the patient, this study supports the view that the patient's subjective acne severity rating may be at least as important to consider as physician-reported severity [1, 31, 32].

One of the main strengths of this study is that the in-depth qualitative interviews conducted prior to the quantitative survey provided impactful data about experiences and perceptions of living with CA. The inclusion of verbatim quotations from the qualitative research provided opportunities to clarify links between data, interpretation and conclusions, thus enhancing the relevance of findings. Further, these quotations provide the opportunity to give participants a voice. Throughout the

process, we triangulated the quantitative data with the qualitative data, the existing literature and peer debriefing. We argue that the convergence of information from different sources increases the validity of our findings.

The present study has a few limitations. The cross-sectional design of this study establishes association, not causation. Acne severity was self-reported; however, to minimise risk of misdiagnosis or misclassification, participants had a diagnosis of acne by a physician, were currently being followed by an HCP and were receiving prescription treatment for acne and had papules and/or pustules at the time of study procedures [33–35]. Photographs with examples of acne (e.g. comedones, papules, pustules and nodules) were provided in the quantitative survey to assist self-recognition, and standardised photo-scales were provided in the quantitative survey as examples of acne severity on the face, chest and back along with text descriptions in participant's language. The study used a combination of deductive and inductive methods for the initial item generation, and its content validity was assessed by two independent clinical experts. However, the construct validity and reliability of the survey was not assessed.

Overall, acne is associated with considerable psychological morbidity. Decreased self-image and self-esteem associated with both facial and truncal acne were linked to embarrassment, self-consciousness, shame and, consequently, avoidance behaviour. This morbidity is complex with several exacerbating (e.g. perceived stigma) and attenuating factors (e.g. acne being perceived as being under control) that should be taken into account in the management of these patients.

CONCLUSIONS

CA is associated with considerable psychological morbidity, with several exacerbating (e.g. perceived stigma) and attenuating factors (e.g. acne being perceived as being under control) that should be accounted for in CA management. Uncontrolled facial and/or truncal acne

negatively impacted the emotional wellbeing and daily life activities of afflicted individuals.

ACKNOWLEDGEMENTS

Funding. This research was sponsored and funded by Galderma. The study sponsor is also funding the journal's Rapid Service Fee (6890000692).

Medical writing and editorial assistance. Medical writing and editorial assistance were provided by Dr Angeles Brooks, Kantar Health (France) and funded by Galderma.

Author contributions. JT, SB, FCB, JH, AH, EL, AL, JW and BD: analysis, drafting the manuscript. RC: concept and design, analysis, drafting the manuscript.

Disclosures. Jerry Tan has acted as a consultant for and/or received grants/honoraria from Bausch, Galderma, Pfizer, Almirall, Boots/Walgreens, Botanix, CIPHER, Galderma, Novan, Novartis, Promius, Sun, Vichy. Stefan Beisert has acted as an advisor for Abbvie Deutschland GmbH & Co, Actelion Pharmaceuticals GmbH, Allmirall-Hermal GmbH, Amgen GmbH, Celgene GmbH, Galderma Laboratorium GmbH, Janssen-Cilag GmbH, Leo Pharma GmbH, Lilly Deutschland GmbH, Menlo Therapeutics, MSD Sharp & Dohme GmbH, Novartis Pharma GmbH, Pfizer Pharma GmbH, Sanofi-Aventis Deutschland GmbH, UCB Pharma GmbH, and has received speaker honorarium from Novartis Pharma GmbH, Abbvie, MSD, Pfizer, Janssen-Cilag, Roche-Posay, Actelion, GSK, BMS, Celgene, Allmirall, Hexal-Sandoz. Fran Cook-Bolden has acted as an advisor, consultant, investigator and/or speaker and received grants/honoraria from Almirall, Cassiopea, Foamix Pharmaceuticals, Galderma and Ortho Dermatologics. Rajeev Chavda is an employee of Galderma. Julie Harper has acted as an advisor, consultant, and/or speaker and received honoraria from Almirall, BioPharmX, Cassiopeia, Cutanea, Cutera, Dermira, EPI Health, Galderma, LaRoche-Posay, Ortho Dermatologics,

Sol Gel, Sun and Vyne. Adelaide Hebert has acted as an advisor, consultant, investigator and/or speaker and received grants/honoraria from Allergan, Cassiopea, Galderma, GSK, La Roche-Posay, Novan, Ortho Dermatologics, Ortho Dermatologics, Regeneron Sanofi and Vyne. Edward Lain has acted as an advisor, consultant, investigator and/or speaker and received grants/honoraria from AbbVie, Aclaris Therapeutics Inc., Allergan Inc., Almirall, AstraZeneca, Athenix, Biopelle Inc., BioPharmX, Biorasi LLC, BMS, Brickell Biotech Inc., Cassiopea S.p.A., Celgene, Cellceutix, ChemoCentryx, Cutanea Life Sciences, Demira, Dow Pharmaceutical Sciences Inc., Dr Reddy's Laboratory, Eli Lilly and Company, Gage Development Company LLC, Galderma Laboratories L.P., Galderma USA, Hovione, Kadmon Corporation LLC, La Roche-Posay, LEO Pharma, Medimmune, Menlo Therapeutics, Moleculin LLC, Neothetics, Nielsen Holdings N.V, Novartis, Ortho Dermatologics, Pfizer Inc., Promius Pharma LLC, Sebacia Inc., Sienna Labs Inc., SkinCeuticals LLC, Sol-Gel Technologies, UCB and Valeant Pharmaceuticals North America LLC. Alison Layton has acted as an advisor, consultant, investigator and/or speaker and received grants/honoraria from Galderma, GSK, L'Oreal, La Roche Posay, Origimm, Leo Pharma and Proctor & Gamble. Marco Rocha has acted as an advisor and/or speaker and received honoraria from Eucerin, Galderma, Johnson&Johnson and Leo Pharma. Jonathan Weiss has acted as an advisor, consultant, investigator and/or speaker and received grants/honoraria from Almirall, Bausch, Cassiopea, Cutera, EPI Health, Foamix, Galderma and Ortho Dermatologics. Brigitte Dréno has acted as an advisor, consultant and/or speaker and received honoraria from BMS, Galderma, La Roche-Posay, Merck Serono, Pierre Fabre and Sanofi.

Compliance with ethics guidelines. All adult subjects provided informed consent prior to participation. Legal guardians gave consent for individuals who were younger than 18 years. Assent from paediatric participants was also obtained. The study received a favourable opinion by the Kantar Internal IRB/Ethics Committee and was performed in accordance

with the Helsinki Declaration of 1964 and its later amendments. Local specialised qualitative researchers conducted the in-depth interviews, and the authors thank the study participants for their participation in this study.

Data availability. The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

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