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## Tracking tumor kinetics in patients with germline *CYLD* mutations

*To the Editor:* Objective data on the rate of growth of skin tumors in the rare orphan disease CYLD cutaneous syndrome (CCS; synonym Brooke-Spiegler syndrome) are lacking. Its clinical burden on patients is significant, warranting the clinical trial of personalized treatments. To inform the design of trials of novel therapies, natural history studies that capture the rate of tumor growth in CCS are needed. The absence of such data on this rare genetic disease prompted our work to gather opportunistic tumor measurements from radiologic investigations carried out in patients with CCS as part of their routine clinical care.

Here we report the rate of tumor growth in 3 patients with CCS who underwent serial computed tomography (CT) imaging for monitoring pulmonary cylindromas[1,2] or malignant tumors. Four individuals were identified as having undergone CT imaging following a retrospective case note and radiologic data review of 16 CCS patients attending a tertiary dermatogenetics center, 3 of whom had CT-detectable tumors.[3,4] These 3 females had been documented to carry a familial heterozygous mutation in the *CYLD* gene (c.2460delC).[5] They had features of a severe phenotype, including a history of complete scalp excision in 2 of them. Ethical approval to study these patients (who had given consent) was obtained from a research ethics committee.

In each patient, tumors were located and numbered on a baseline high-resolution CT scan. Each tumor was measured on every slice on which it was visible, after which the longest diameter measured was chosen for each time point. This axis of measurement was maintained on subsequent imaging. We elected to exclude tumors smaller than 3 mm, lesions seen on only 1 slice, confluent tumors, and tumors arising in scar tissue (as this tissue was often isodense to the tumor) to allow for maximal accuracy and reproducibility across all scans. Data from new lesions detected during interval scans were included from the point of first appearance and tracked in subsequent scans. Excised lesions for which more than 1 time point was measured were tracked to the point immediately before excision; tumors that were seen at only 1 measurement time point were excluded, as they did not contribute to the rate of change data. Relative changes in size were calculated by comparing measurements at the indicated time points against baseline. Patients were followed over a mean period of 495.6 days (range, 226-891 days).

Of the cutaneous cylindromas, 30 grew and 2 decreased in size during the period of observation. The mean size at baseline was 12.6 mm (range, 6.7-23.5 mm) (Fig 1, *A*). The average increase in size of cutaneous tumors was 12.6% (range, −8.7% to 41.1%) per year (Fig 1, *B*). Fourteen pulmonary cylindromas were studied; all of them increased in size. The mean size of the pulmonary tumors at baseline was 18.7 mm (range, 4.4-42.7 mm) (Fig 1, *A*). The average increase in size of the pulmonary tumors was 16.3% (range, 1.1%-38.0%) per year (Fig 1, *B*).

Our findings are important for the following reasons. First, these data may inform routine clinical surveillance intervals, with insights into both cutaneous and pulmonary tumor kinetics. Second, our approach is informative as a proof of principle that serial radiologic imaging can be used to monitor change in the size of cutaneous tumors in this

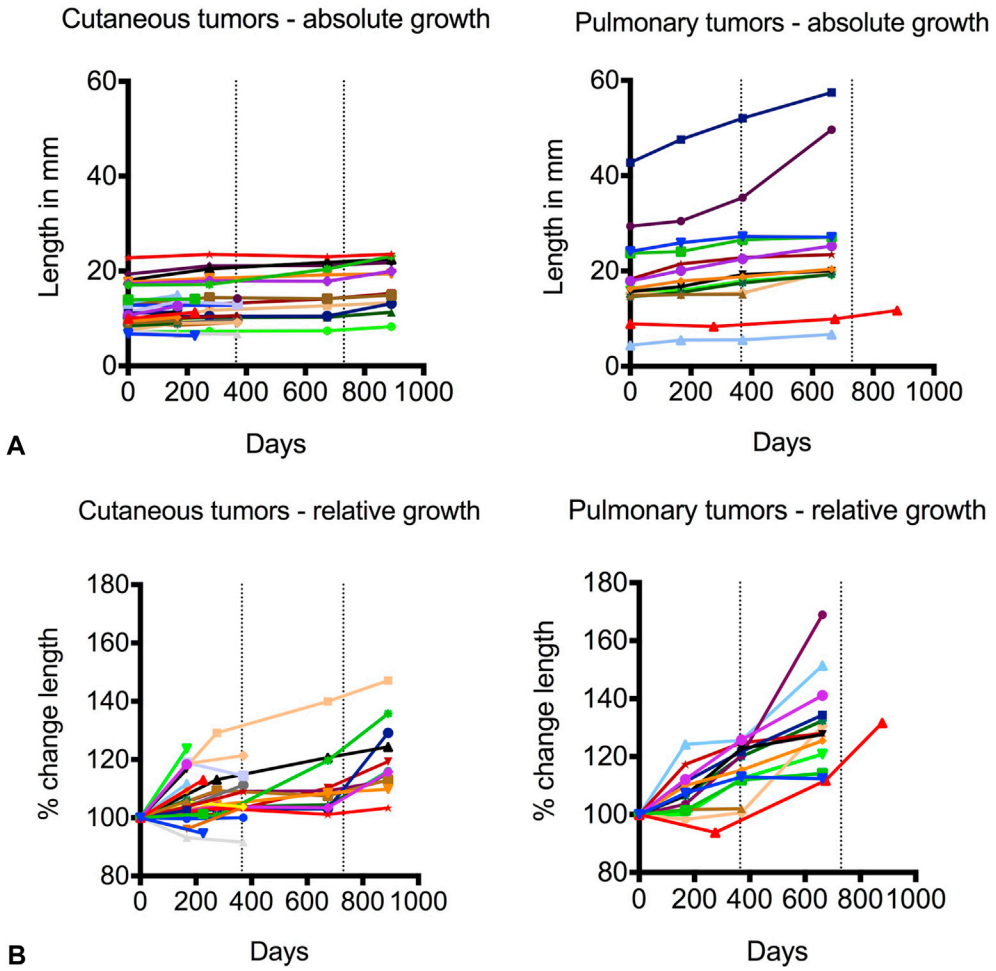


**Fig 1.** Cylindroma. Growth kinetics of cutaneous and pulmonary tumors. **A,** Line graph indicating changes in the longest dimension (in mm) displayed over time for cutaneous and pulmonary tumors. **B,** Line graph showing tumor growth kinetics as percentage change in the longest dimension compared with baseline over time in cutaneous and pulmonary cylindromas. (Dotted lines on *x* axis indicate 1- and 2-year intervals.)

condition. Taken together with anticipated growth rates, this will inform the design and development of meaningful measures of clinical trial outcomes.

Our preliminary data on growth rate is informative; however, caveats that should be considered include patient genotype, body site–specific factors, and excision bias. Nonetheless, our work leverages the multiplicity of lesions seen in these patients and represents opportunistic insight into the tumor kinetics of these rare cutaneous tumors.

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## Bringing big data from social media reviews to quality improvement

*To the Editor:* With the increasing popularity of social media, hospitals are seeing a rise in the use of such platforms for the collection of patient feedback.[1,2] Despite the presence of dermatologic organizations on social media,[3] there are few data on social media as a quality improvement (QI) tool in dermatology. We therefore sought to evaluate the potential for obtaining QI data from Facebook Reviews, as used by academic and commercial dermatology practices.

We performed qualitative content analysis by using a codebook developed from a prior study.[2] First, using the Association of American Medical Colleges list of residency programs,[4] we discovered that 18 of 116 academic dermatology practices (15.5%) had a Facebook page. Of the 18 practices, 14 (77.8%) had Reviews activated (Table I). For comparison, we analyzed the first 14 commercial dermatology Facebook pages with Reviews activated that we identified from a search for *dermatology* in Facebook. The mean number of reviews was 9 (standard deviation, 9) for academic pages and 43 (standard deviation, 53) for commercial pages ($P = .03$).

The most frequent positive comments were similar between academic and commercial practices and included compliments of the staff (most often regarding demeanor) (60.9% vs 62.4%), specific acknowledgments of personnel (48.8% vs 54.9%), and satisfaction with treatment (12.2% vs 19.7%) (Table II). Negative feedback differed between academic and commercial practices, as might be expected given different types of practices. The most frequent negative comments for academic practices included long wait times, poor follow-up, and parking difficulties, and the most frequent negative comments for commercial practices included billing issues, staff complaints (most often regarding poor communication), and long wait times.

These data demonstrate the potential of qualitative content analysis in extracting practical information from patient feedback on social media. With increasing emphasis on quality in health care reimbursements, patient feedback becomes an important source of QI information. To date, to collect feedback, dermatologists have used a variety of online surveys that require patients to maneuver an unfamiliar interface, which may hinder response rates.[5] Answers are also limited to subjects addressed by specific questions. With the wider accessibility and narrative format of Facebook Reviews and other social media review platforms, dermatology practices could accumulate a large volume of narrative data that could then be mined for signals by using qualitative content analysis. Given the real-time nature of social media data, this analysis could be automated by using computer algorithms to warn of results from traditional surveys that are tied to reimbursement, as has been suggested for hospitals and Hospital Consumer Assessment of Healthcare Providers and Systems results.[1,2]

In light of these promising applications of social media data, academic dermatology practices should consider promoting their use of Facebook Reviews. Compared with their commercial counterparts, academic dermatology Facebook pages receive fewer reviews and see much less traffic in general, as is evidenced by the significantly smaller numbers

**Table I.** General characteristics of academic and commercial dermatology Facebook pages

| Characteristic | Academic dermatology | Commercial dermatology | *P* value |
|---|---|---|---|
| Facebook pages, n | 18 | | |
| Pages with Facebook Reviews activated, n (%) | 14 (77.8) | 14 | |
| Average rating, points (SD) | 4.6 (0.4) | 4.6 (0.5) | .99 |
| Average reviews, n (SD) | 9 (9) | 43 (53) | .03 |
| Average page likes, n (SD) | 398 (620) | 1950 (1992) | <.01 |
| Average page followers, n (SD) | 396 (615) | 1945 (1993) | <.01 |

*SD*, Standard deviation.