



The Changing Tasks of Medicine and Dermatology in the Twenty-First Century: The Need for Improved Information Capture Tools and Processes

Howa Yeung · Yin Li · Robert A. Swerlick

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ABSTRACT

The delivery of dermatology services has undergone dramatic changes in the past century. The goals and timelines of care have evolved as have the diagnostic and therapeutic tools, resulting in the need to capture and manage information differently, both qualitatively and quantitatively. The predominant and basic office-based ambulatory care model has remained relatively unchanged. Patients and providers interact with minimal pre-visit preparation using the “agenda-less” meeting model. This care model is ill-suited to manage the vastly expanded data capture and processing requirement of twenty-first century dermatology. We have developed novel tools to automate pre-visit data collection which allows for more robust information capture which moves data capture outside of the time-constrained clinic visit. These tools capture structured data, integrate into electronic health

records, and create summary reports in real time to assist decision-making. These tools, if scaled, can facilitate the information management needs of dermatology care.

Keywords: Quality of life; Questionnaire; Patient-reported outcome; Patient goals; Information science; Electronic health records; Workflow; Performance improvement

Key Summary Points

Why carry out this study?

Improved tools for data capture and documentation will improve clinical care and decrease care team burnout in dermatology.

How can we improve data capture required for outpatient clinical encounters in dermatology practice?

What was learned from this study?

We can use electronic data capture tools to automate data capture in dermatology practice without disruptions of clinical workflows.

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H. Yeung · R. A. Swerlick (✉)
Department of Dermatology, Emory University
School of Medicine, Atlanta, GA, USA
e-mail: rswerli@emory.edu

Y. Li
Nell Hodgson Woodruff School of Nursing, Emory
University, Atlanta, GA, USA

INTRODUCTION

The delivery of medical care has been transformed over the past century. Life expectancy in the USA grew at an extraordinary rate, almost doubling since 1900. These advancements were driven by improvements in public health, increases in standards of living, and improvement in medical technologies. While some of the medical problems faced in 1920 persist, the nature of the deliverables expected and needed from healthcare systems is very different from what they were 100 years ago. One hundred years ago medical care focused primarily on management of acute conditions with success or failure realized over relatively short timelines whereas care now involves management of chronic diseases over much longer timelines [1].

HISTORICAL PERSPECTIVES ON DERMATOLOGIC CARE

Throughout much of the twentieth century, dermatologists cared for only a small fraction of the population. Trained dermatologists were very limited in number and were concentrated primarily in selected large urban centers in affluent nations. Most people did not have the financial resources to see specialty physicians, and the limited health insurance products used to pay for care focused primarily on inpatient care. The diagnostic tools dermatologists had at their disposal were limited to their eyes, either looking at skin or, to a more limited degree, histological morphology. While it may have been very satisfying to use a dermatologist's trained eyes to make fine diagnostic distinctions, the treatment options at that time converged on a very limited set of treatment options which were, at best, modestly effective. The information base required to manage individual patients with skin diseases was acquired with years of training and experience, and its repository was primarily in the brains of those practicing [2].

In the latter portion of the twentieth century, a sea of change resulted in large increases in the numbers of people seeking care from dermatologists. These included a marked

expansion of the pool of dermatologists available to deliver care, an explosion of diagnostic and therapeutic tools available to diagnose and treat skin disease, a marked increase in disposable income and resources available to pay for outpatient dermatological care, and ongoing expectation changes of what the goals of healthcare could and should be. Whereas our grandparents and great grandparents sought care from their doctor only when they were gravely ill and were quite happy when they did not die, we now expect so much more from our health systems, including dermatologists.

INCREASING STRESS ON OLD CARE MODELS

Despite these dramatic changes in the tools and goals of care, the basic dermatology ambulatory care delivery model has remained essentially unchanged. Patients make appointments and come to dermatology offices where both the patient and doctor do minimal preparation before any encounter [3]. Medical visits for the most part represent agenda-less meetings. Data collection relevant to any visit happens once patients reach the exam room. However, increasing management choices for chronic skin conditions require more information than was required in the past—more than what can be realistically collected and processed during time-constrained office visits. Furthermore, the increasing expense of care delivery has pushed for increased clinical volumes (euphemistically termed productivity) and magnified time constraints of office visits. This all is occurring simultaneously with an ongoing information explosion requiring more data collection and data management. The historical model of care delivery cannot accommodate this.

As the goals of care evolve and we aspire to manage of chronic illness and disease risk states, the need for more robust data capture has only increased [2]. Furthermore, artificial intelligence (AI) has captured the imaginations of the public, clinicians, researchers, and policy makers in processing large amounts of clinical data to support and optimize patient care decisions. However, missing from the AI conversation as it

relates to dermatology are the data inputs. For AI to meaningfully impact care in dermatology, the quality of the data inputs in clinical practice needs to improve. AI is trained on existing datasets, which are often manually inputted by clinicians for documentation or billing purposes that lack structure or validation. AI trained from flawed datasets will render a different form of AI, artificial ignorance.

DEFINING THE DATA CAPTURE PROBLEM: THE WHAT AND THE HOW

Despite the apparent complexity, there are simple principles which can guide how we address these data challenges. We must define *what* data we need to collect and *how* we collect it in such a way that this does not disrupt clinic workflows. Dr. Larry Weed, developer of SOAP note and the problem-oriented medical record concepts, articulated this more than 40 years ago [4]. He stressed that before decision-making is undertaken in any given encounter, a consistent database, relevant to the problem at hand, needs to be captured. While this appears to be conceptually simple, actual deployment has not been accomplished because the minimum data to be captured has not been fully defined, the technologies and workflows to collect the data without workflow disruptions have not been created, and the value proposition to create this infrastructure has been lacking.

Defining the key data elements that should be collected requires us to focus on two basic sets of questions. The first set of questions involves the information that is required to define diagnosis and treatment. Is this an acute or chronic problem? What diagnostic tests and treatments have already been undertaken? From the patient's perspective, what is the most bothersome/disturbing aspect of the skin disorder? Is treatment desired? What are the goals of treatment? Which treatment is optimal given the specific disease and patient goals?

Once these data have been collected and acted upon, the next set of questions to be addressed focuses on measuring responses to

treatment and the data needed to assess those responses to intervention. Has the patient's skin disease improved? Is the treatment provided adequate? Has the patient been harmed? Some of these data points can be measured objectively by the treating physician. What is the body surface area involvement? What is the provider global assessment? Other endpoints can and should be patient-defined. What are the itch and pain scores? What is the patient's global assessment of their disease? What is the impact of the disease on a patient's quality of life (QOL)? Patient-reported outcomes (PRO) measurements, such as the Skindex, ItchyQoL, or Dermatology Life Quality Index (DLQI), can capture patient illness experience and QOL across a broad range of skin diseases [5–7]. However, these tools have been deployed only on a very limited basis in clinical practice [5, 8, 9].

We created an abbreviated three-question form of the Skindex tool, which we called the SkindexMini to briefly capture skin illness burden in symptom, emotional, and functional domains [6, 10]. We combined the SkindexMini with itch scoring, pain scores, patient global assessment of disease, and patient assessment of treatment adequacy, creating a nine-question tool which we termed the standardized dermatology outcomes measure (SDOM; see supplementary material). This tool targets collection of critical subjective information that may be missed by physicians leading to underestimating the severity and impact of skin disease [11, 12].

EARLY EXPERIENCES AT THE EMORY CLINIC

We conducted pilot testing on how to collect this information without disrupting care. This work was granted exempt status by the Emory Institutional Review Board. This article is based on previously conducted studies and does not contain any new studies with human participants or animals performed by any of the authors.

For our initial forays into data capture, we used paper forms for patients to complete at the

beginning of their clinic visits. Paper forms were easy to deploy and modify as needed. We evaluated whether these activities were perceived as being disruptive of clinic workflows. Initially, there were concerns when the SDOM was deployed, but subsequent surveys of faculty and staff showed neutral effect of paper-based surveys on clinic flow.

To optimally leverage the data captured using paper-based surveys, ideally the information should be transcribed into structured fields within the electronic health record (EHR) and stored within a clinical data warehouse. This will facilitate information to be incorporated into encounter notes and be tracking over time for individual patients and for the practice in aggregate. While patients completed the paper-based surveys in clinics, there was not sufficient time during busy clinic visits to add the additional tasks associated with electronic data entry. Neither clinician nor staff were willing to key in additional data as part of routine workflows. We were able to come to a consensus as to what data we should collect but we were stymied by how to collect it in such a way that it could be captured and used for clinical decision-making and treatment response tracking over time.

The obvious solution to address this data entry problem is to empower patients to directly input data, which shifts data entry tasks to times outside of the time-constrained clinic visit. This approach has been piloted in primary care and on a very limited basis in dermatology [13, 14]. We tested pre-visit data capture using a third-party survey platform, Tonic for Health, which allowed the capture of data from patients before clinic visits. Links to surveys could be sent out via text or email before scheduled clinic visits and the results of the surveys were automatically incorporated into the medical record at the time of the visit. On the basis of pre-existing-based questionnaires, we created electronic surveys which incorporated branching logic, allowing for different questions to be served to patients with different reasons for their dermatology visits.

For general dermatology, we created generic New and Established patient questionnaires. Each of the questionnaires incorporated branching logic which prompted answering

different questions for patients with different reasons for visits (see supplementary material for New and Established patient questionnaires). Initial questions were focused on specific reasons for visits which then triggered the use of branched logic (Fig. 1). For patients with inflammatory skin diseases (e.g., eczema) or stigmatizing skin diseases (e.g., alopecia or vitiligo), they were queried regarding what bothered them most about their skin issues (symptoms, appearance, worry about associated disease, or other), and presented with the SDOM.

From March 10, 2021 to August 1, 2022, we collected 10,388 established patient surveys and 5086 new patient survey responses. The overall response rates were 48.8% and 55.0% respectively for established and new patients. Survey notifications were successfully delivered to 90.1% of patients using a combination of texts and emails. For new patients, depending upon the pathway selected, the survey required on average 5.0 min to fill out for new patients presenting for skin check, 6.4 min for patients with specific concerning spots, and 8.7 min for patients requiring an evaluation for inflammatory skin disorders. For follow-up patients, the average skin check patient required less than a minute to complete, spot checks 2.2 min, and remaining patients 5.8 min (Table 1).

LESSONS LEARNED, CHALLENGES, AND NEXT STEPS

We learned that it is clearly feasible to collect important information before office visits using an automated process which, once initiated, required little or no additional clinician or staff time. Although not universally embraced by patients, we were able to garner substantial engagement from patients with limited to no marketing efforts. In developing these questionnaires, we attempted to navigate a pathway between comprehensiveness and efficiency, understanding that too many questions quickly reached a point of diminishing returns. In addition, we aimed to capture data in structured formats and avoided free-text answers whenever possible. Capture of the data was necessary but



Fig. 1 Selected question panels from Tonic for Health surveys used

not sufficient without a plan to be able to effectively display to decision makers in ways to support decision-making and care. The Tonic survey data captured was incorporated into a pdf document and filed in the EHR (supplementary material).

For this approach to scale and become widely adopted, stakeholders need to see that it will bring value to them. Starting with patients, they need to experience that taking the time to engage in pre-visit data collection will translate into better care experiences and better treatment outcomes. Surveys used must ask questions that make intuitive sense to those being queried. It will also require consistent review of patient-entered data by care teams and acknowledgement of their inputs when care decisions are rendered.

For dermatologists to embrace this approach, it must enhance their work. The information collected needs to be the information required to be efficient, make better decisions, and to provide near real-time feedback on the effectiveness of interventions. These activities must help alleviate the drudgery driven by relentless production pressures and not be perceived as making things worse. Better information relevant to clinical decisions, collected outside of time pressured clinic visits, and presented in ways to enhance decisions and documentation can restore the joy of practice while also capturing data that supports quality improvement and research efforts.

Table 1 Time (minutes) required to fill out new and established patient surveys

	New patient		Established patient	
	Time to complete (mins)	SD	Time to complete (mins)	SD
Overall	6.5	5.1	3.4	3.9
Skin check	5.0	5.0	0.96	0.6
Spot check	6.4	5.4	2.2	1.8
Other ^a	8.7	5.4	5.8	4.3

^aSee Fig. 1 for other skin concerns

The next steps required to scale this initiative require both additional patient engagement and engagement from healthcare delivery teams. This reflects the reality that healthcare outcomes are not created by health systems to be delivered to passive recipients but, in contrast, outcomes are optimally co-produced by patients and healthcare teams working together [15]. Convincing all parties of the value proposition and their roles will not be easy but we believe it is doable. For patients, it can enhance their ability to effectively communicate their concerns and goals. For dermatologists, it provides a pathway to better manage the tsunamis of information which has become an undeniable part of patient care.

The ultimate value proposition for all parties involved is the creation/evolution of care delivery systems which are more efficient, functional, and effective. While medicine has been transformed by a myriad of novel pharmaceuticals, devices, and procedures, the current underlying care model based upon “agenda-less” meetings (appointments) is not scalable. Twenty-first century healthcare is remarkable in what it can potentially do to alleviate suffering and disease. However, the underlying care delivery models must evolve in order scale and allow for more people to benefit from all the transformational knowledge and technologies. Applying existing implementation science theories can help understand, facilitate, and optimize how to adopt, implement, adapt, and maintain the use of electronic structured data collection tools for patient-reported outcomes across real-life dermatology practice settings [16].

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

Declarations

Conflict of Interest. Robert A. Swerlick has nothing to disclose. Howa Yeung has nothing to disclose. Yin Li has nothing to disclose.

Ethical Approval. This work was granted exempted status by the Emory Institutional Review Board. This article is based on previously conducted studies and does not contain any new studies with human participants or animals performed by any of the authors.

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