Continuous Glucose Monitoring in the Real-World:
Photosurveillance of #Dexcom on Instagram

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Introduction

Individuals with diabetes are using social media as a method to share and gather information about their health via the diabetes online community. The diabetes online community is a grassroots collection of individuals affected by diabetes who use internet resources (i.e. forums, Facebook, Twitter) to discuss health-related issues [1, 2]. One social media site used within the diabetes online community that supports photo sharing is Instagram. If a picture is worth a thousand words, a diabetes-related photo posted on Instagram is worth a million ‘likes’. Diabetes online community users can optimize diabetes-related conversations on Instagram through the use of hashtags.

One technology that individuals with diabetes use to support self-care is real-time continuous glucose monitoring (CGM). CGM is comprised of a small sensor placed into the subcutaneous tissue, a transmitter, and a receiver or smartphone that display glucose levels and trends in real time. One of the two companies that supply CGM monitors for patient use is Dexcom®. Currently, the Dexcom® is Food & Drug Administration (FDA) approved to be worn on the abdomen only for adults, and abdomen or buttocks for children. Further, the Dexcom® is FDA approved to be worn for 7 days. Through clinical observation and anecdotal reports, patients are wearing CGM in off-label sites and extending the wear beyond 7 days. However, we do not know the extent to which CGM users are using off-label site locations or for how long.

Infoveillance is one methodological approach to examine healthcare trends [3, 4]. This approach, which overlays Twitter data and geographic data, has been successful in identifying infectious diseases, such as influenza [5, 6], zika [7], and suicide in veterans [8, 9]. Infoveillance, while very effective in identifying many real-world health trends, may miss opportunities which use photographs as primary sources for data. We propose a new methodology, photosurveillance, in which photographs are analyzed to examine real-world trends. Photographs represent micro-reports of events of day-to-day life [10], such as diabetes management. Since some CGM users are sharing photographs of their diabetes experiences online, analyzing Instagram using a photosurveillance approach can help observe real-world use of CGM. The purpose of this research is to 1) assess the use of photosurveillance as a research method to examine real-world trends in diabetes, and 2) report on real-world use of continuous glucose monitoring on Instagram.

Methods

Data Set Acquisition and Sampling

This study was acknowledged as exempt by the University of Utah ethics board. This descriptive study was conducted by hand searching all photographs (N=2923) posted on Instagram identified with the hashtag, #dexcom, over a 3-month period (December 2016 – February 2017). The hashtag #dexcom was chosen because it was more commonly used (N=46,105) when compared to other Dexcom® related hashtags (#dexcomg5 N=8,350; #dexcomg4 N=6,135; #dexcomcgm N=1,105). Photographs were included for analysis if they depicted a CGM site and the original post was written in English (N=353). Photographs were excluded if they included a CGM site but were...
initiated from a company advertising their product (i.e., adhesive decal).

Photograph Analysis

Photosurveillance was conducted by categorizing photographs by site location, including FDA approved (in adults, this includes the abdomen only) and off-label sites (in adults this includes the posterior arm, anterior arm, forearm, back, buttocks, thigh, calf), and “other”. The “other” category represented photos of a CGM on skin without clear body landmarks (i.e. hand, foot, belly button) that identified the exact location. Two independent researchers input data into REDCap, a web-based data capture program, to organize data [11]. Text from the original posts were analyzed to support data input. A content analysis approach was utilized in which counts are categorized. Frequencies are used to describe the differences between FDA approved and off-label activity.

Post and Comment Analysis

Original posts (N=353) and corresponding comments (N=2364) were analyzed to examine discussions related to CGM activity. Comments were initially read and reread by two investigators to develop the initial coding schema using an open code approach. Successful CGM use was determined if the comment provided affirmation that a specific CGM site location worked for them. CGM failure was categorized by inaccurate readings (i.e., CGM readings did not match glucometer readings in a way that was significant to the user), CGM ripping or falling off, too painful to continue wearing, bleeding impacting use, and unknown. If the post or comment did not affirm success or failure, it was coded as not applicable. Post or comment mentions of off-label use of CGM wear >7 days was examined. Data was categorized for every 7 days worn beyond FDA approval (i.e., 8-14 days, 15-21 days, etc.).

Qualitative Thematic Analysis

Qualitative thematic analysis was conducted by examining each original post (N=353) and corresponding comments (N=2364). Codes were used to organize similar data in order to identify discussions about FDA approved and off-label CGM activity [12]. The codes were then systematically applied to all of the data using an open code approach to capture any data that was not specific to FDA approved or off-label CGM activity [12, 13]. A matrix was created to maintain an audit trail [14]. Themes were developed from the data [15]. Content of data, and not code frequency, was used to assess data saturation [16]. To avoid risk of identification, no direct quotes were used in this manuscript.

Results

Photograph Analysis
Of the 2923 photographs examined during the study period, 12.1% (N=353) depicted a photograph with a CGM site location. The majority (64%, n=225) of the photographs showed CGM sites in off-label locations, while 26.2% where in an FDA approved location (abdomen), and 10.2% (n=36) were in unidentifiable locations (i.e., “other” category, see Table 1). There were no significant differences in the number of likes (FDA approved N=9,152, off-label N=24,534; p=.851) or comments (FDA approved N=707, off-label N=1500; p=.159) based on FDA approval (see Table 2). However, the volume of likes and comments were 3-4 times greater for off-label locations.

Table 1. Instagram Photographs by CGM Site (N=353)

<table>
<thead>
<tr>
<th>CGM Site Location</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Posterior Arm</td>
<td>139 (39.4)</td>
</tr>
<tr>
<td>Abdomen (FDA approved)</td>
<td>92 (25.1)</td>
</tr>
<tr>
<td>Thigh</td>
<td>45 (12.7)</td>
</tr>
<tr>
<td>Other</td>
<td>36 (10.2)</td>
</tr>
<tr>
<td>Forearm</td>
<td>12 (3.4)</td>
</tr>
<tr>
<td>Back</td>
<td>10 (2.8)</td>
</tr>
<tr>
<td>Anterior Arm</td>
<td>10 (2.8)</td>
</tr>
<tr>
<td>Calf</td>
<td>7 (2)</td>
</tr>
<tr>
<td>Buttocks</td>
<td>3 (0.6)</td>
</tr>
<tr>
<td>TOTAL</td>
<td>353 (100)</td>
</tr>
</tbody>
</table>

Table 2. Engagement with Off-Label and FDA Approved CGM Site Posts

<table>
<thead>
<tr>
<th></th>
<th>Off-Label</th>
<th>FDA Approved</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Likes</td>
<td>13,612</td>
<td>4,365</td>
<td>.851</td>
</tr>
<tr>
<td>Comments</td>
<td>1,395</td>
<td>357</td>
<td>.159</td>
</tr>
</tbody>
</table>

Post and Comment Analysis

Original posts (N=353) and comments (N=2364) captured discussions about successful CGM use and failures. Success rates were similar in the abdomen and
posterior arm (Table 3). Inaccuracy concerns were noted more often in the abdomen, calf, and buttocks, although the sample size of the buttocks was relatively low (N=10). There were N=40 individual users who noted wearing their CGM successfully > 7 days, see Figure 1.

Table 3. CGM Site Discussions Based on Success and Failure Rates*

<table>
<thead>
<tr>
<th>Site</th>
<th>Success Rates</th>
<th>Inaccurate N(%)</th>
<th>Ripped or Fell Off N(%)</th>
<th>Too Painful N(%)</th>
<th>Bleed N(%)</th>
<th>Unknown Reason N(%)</th>
<th>Unable to Determine N(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abdomen (N=178)</td>
<td>137 (77)</td>
<td>11 (6.2)</td>
<td>3 (1.7)</td>
<td>6 (3.4)</td>
<td>0 (0)</td>
<td>1 (0.6)</td>
<td>20 (10.7)</td>
</tr>
<tr>
<td>Post Arm (N=273)</td>
<td>218 (79.9)</td>
<td>6 (2.2)</td>
<td>3 (1.1)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>2 (0.7)</td>
<td>44 (16.1)</td>
</tr>
<tr>
<td>Thigh (N=198)</td>
<td>137 (69.2)</td>
<td>6 (3.3)</td>
<td>2 (1)</td>
<td>0 (0)</td>
<td>5 (2.5)</td>
<td>3 (1.5)</td>
<td>45 (22.7)</td>
</tr>
<tr>
<td>Back (N=42)</td>
<td>24 (57.1)</td>
<td>2 (4.8)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>16 (38.1)</td>
</tr>
<tr>
<td>Calf (N=48)</td>
<td>20 (41.7)</td>
<td>3 (6.2)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (2.1)</td>
<td>0 (0)</td>
<td>24 (50)</td>
</tr>
<tr>
<td>Ant Arm (N=30)</td>
<td>19 (63.3)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>1 (3.3)</td>
<td>0 (0)</td>
<td>10 (33.3)</td>
</tr>
<tr>
<td>Forearm (N=38)</td>
<td>22 (57.9)</td>
<td>0 (0)</td>
<td>1 (2.6)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>15 (39.5)</td>
</tr>
<tr>
<td>Buttocks (N=10)</td>
<td>6 (60)</td>
<td>1 (10)</td>
<td>1 (10)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>2 (20)</td>
</tr>
</tbody>
</table>

Figure 1. Reported CGM Use >7 Days (N=40)
Qualitative Thematic Analysis

Four themes emerged from the analysis of original Instagram posts and the corresponding comments: 1) endorsement of CGM as providing a sense of wellbeing, 2) reciprocating encouragement and support, and 3) life hacks to optimize CGM use, and 4) sharing and learning about off-label CGM activity.

Endorsement of CGM Providing a Sense of Wellbeing

CGM was described as a life saver. Hypoglycemia alarms were valued more than hyperglycemia alarms with regards to immediate safety concerns. Several posts mentioned the CGM ‘share’ feature providing a peace of mind for loved ones. Care partners who visualized glucose levels provided support to those with diabetes who reported they could confidently engage in day-to-day activities, such as exercise and sleep. Individuals described a willingness to continue use of CGM despite cost and other frustrations they may have experienced because of the assurance CGM provided to them and their loved ones. In fact, individuals felt so strongly about CGM, they used social media as a platform to encourage others with diabetes to use the technology. Social media was also used to teach Instagram followers, who may not have had diabetes, about CGM technology.

Many users shared that using CGM allowed them to think less about their diabetes and confidently manage their health in a less intrusive way. Individuals also mentioned that CGM use reduced their worry by alerting them early to trends of high or low glucose levels. CGM, in some cases, also provided insight into daily trends like...
overnight hypo- or hyperglycemia. Several posts attributed the use of CGM to a reduction in their glycosylated hemoglobin A1c levels and even prolonged life. Social media and photosurveillance allowed for capture of these important qualitative metrics; these would otherwise be difficult or impossible to capture in the clinical trial setting.

Reciprocating Encouragement and Support

Posters and commenters reciprocated feelings of frustration and celebrated success with their peers on Instagram’s #Dexcom. Frustrations usually resulted from costs of managing diabetes, hypo- or hyperglycemia that may or may not have been accompanied by physical symptoms or feelings consistent with diabetes burnout. Several posts included individuals engaging in healthy activities, such as exercise or eating a healthy meal. Peers encouraged others to stay on track, or provided general health advice, such as drinking more water, getting enough rest, and the importance of administering a bolus before meals. Individuals who shared success stories, such as overcoming an emotional or physical barrier, were seen as inspirational. Comments of mutual understanding or motivational messages were provided to those who expressed distress related to their diabetes.

Emojis and hashtags were used to provide encouragement and support. For example, hearts (of all colors) were used in a way to exhibit caring. Hand gesture emojis, such as clapping hands, oncoming fist (fist-bump), OK hand (index finger touching thumb to make an open circle), and victory hand (peace sign) were used to exhibit concordance and approval. Hashtags were used to describe their diabetes (i.e., #T1D, #type1diabetes, #type1lookslikeme) or tools used to manage diabetes (i.e., #insulinpump). Additionally, hashtags were used in fun or humorous tone (i.e., #bionicwoman, #insulinjunkie, #sexybetic).

Life Hacks to Optimize CGM Use

Instagram users shared tips and tricks to help others control the cost of CGM. For example, individuals posted that if the CGM failed in less than 7 days, they should directly contact Dexcom® to request a replacement. Discussions took place related to “precooking” or “soaking” the sensor in order to improve accuracy. This means placing a new sensor on the body for several hours prior to starting the official warmup period on the device. User report that the extended warmup time improves CGM accuracy, addressing the lower accuracy seen within the first 24 hours of CGM use.

Some individuals noted concern about the adhesive not working the full 7-day period or experiences where the CGM had become inadvertently unattached from the body. The use of various adhesives (i.e., GrifGrips, Opsite Flexifit, medical tape) and adhesive barrier wipes (i.e., Skin Tac) were described as a way to improve CGM adherence to the skin. Individuals with concerns about CGM adhesive causing skin rashes were informed about other barriers to prevent skin reactions (i.e., Johnson and Johnson tough pads, 3M Cavilon No Sting Barrier Film).
Some shared pictures of personalizing their CGM with designs as a way to de-
medicalize and accessorize the medical device. Personalization occurred with the
transmitter or receiver (i.e., PumpPeelz), additional adhesive (i.e., GrifGrips), and
Dexcom® receiver (i.e. Tallygear).

Sharing and Learning About Off-Label CGM Activity

Two types of off-label activity were discussed, CGM wear on locations other than
the abdomen and extension of CGM wear beyond 7 days. Off-label CGM activity
discussions included those who had engaged in off-label activity often and those who
had not. Those who had not engaged in off-label activity sometimes reported that they
had only been taught the FDA approved way of wearing CGM and had not thought to
self-experiment. However, use of CGM on body parts other than the abdomen were
oftentimes viewed as exciting and useful. Those who were already using CGM in off-
label locations had typically experimented in more than one off-label location until they
found a site(s) that were both comfortable and provided accurate readings. While some
individuals expressed unwillingness to show their CGM in a location that was more
publicly visible (i.e., arm), many individuals only wearing CGM on the abdomen
indicated they planned to engage in off-label CGM wear in the future.

Details on how to extend the use of the CGM (deactivating the sensor on the
receiver, then activating the previously used sensor that was still intact on the body) was
described on multiple posts and comments. Individuals stated they extended their use
of CGM beyond 7-days for several reasons. First, to save costs. CGM was noted to be
expensive and not having to change CGM sensor on a weekly basis allowed them to
require fewer sensors each month. Additionally, improvement in readings with CGM
wear over a longer period of time was also noted. Curious about this activity, learners
sought more specific details from users experienced with this activity. Similar to off-label
locations, several 7-day CGM users expressed interest in extending CGM wear time in
the future.

Discussion

This is the first study, to our knowledge, that uses photosurveillance, a novel
methodology, to examine the real-world use of CGM. We found that CGM users in this
sample were successfully engaging in off-label activity related to CGM use in order to
improve their experience with the technology. CGM use in location sites that were off-
label yielded, in some instances, better success than FDA approved locations. CGM
wear time was also extended beyond the FDA approved 7-days by some individuals.
Instagram was used as a resource to provide and reciprocate emotional support and
learn about life hacks to optimize CGM use, which included both FDA approved and off-
label activity. Our findings have several implications.

Information about off-label use of CGM is being shared on Instagram. In this
study, individuals wore CGM in off-label locations with greater frequency than the
abdomen and the success rates between the abdomen and posterior arm were similar. A small study in a pediatric population found no accuracy difference in the abdomen, buttocks (both approved by the FDA in children) and arm (off-label) [17]. Further, sensor failure was equal between off-label and FDA approved locations.

Dexcom is typically used by individuals who are dependent on insulin, and therefore need to be protective of the available “real estate” on their body to optimize insulin absorption. The risk for scar tissue and the need to rotate insulin injection/pump sites may increase the desire for multiple areas to place CGM, not just the abdomen. Recent research [18] indicates that CGM placement in areas of lipohypertrophy, which may not necessarily be on the abdomen, has equivalent or superior glucose accuracy to that of normal tissue; however, long-term data is lacking. Currently, 68-71% of CGM users wear their CGM at least 75% of the time [19, 20], it is possible that use of off-label CGM locations may increase this number.

We found instances in which CGM was being worn successfully beyond the FDA-approved 7-days. While the sample size was relatively small (11.3%), the qualitative data indicates that this phenomenon not only contributed to cost savings, but also improved CGM accuracy over time. With the recent FDA approval of the Dexcom G6 in the United States of America, which has a 10-day wear, the extension of use remains to be seen.

We successfully used photosurveillance techniques to examine real-world trends in diabetes care, however, this was a labor-intensive process. Future research should explore machine learning techniques to examine photographs and corresponding text from social media sources on a larger scale. For instance, computer vision algorithms can be leveraged to automatically process images to identify when individuals are wearing their devices in off-label locations. In particular, Convolutional Neural Networks (ConvNets) [21] achieve state-of-the-art accuracy for several computer vision tasks including object recognition, object detection, and scene labeling [22-25]. Labeled Instagram posts that have been manually annotated by human coders can be used to provide training data to calibrate the model, and a test data to evaluate the trained model’s accuracy. Moreover, other types of social media, including Twitter, can be utilized to examine public opinion and sentiment around CGM, and these data can be processed using natural language techniques developed within the field of computer science. Machine learning and deep learning algorithms can potentially decrease the cost of research and enable research to be conducted on a larger scale but may not be able to provide as detailed an analysis on features of an image or text that human coders can provide. While a human coder can evaluate potentially hundreds of characteristics of an image or scene, separate algorithms may need to be built for each characteristic to be extracted.

Limitations

Photographs only capture a snapshot in time and may not accurately reflect CGM use or sensor failure in a larger population. However, our study does confirm
previous work [17] focused on glucose accuracy in off-label locations. To optimize representativeness of our sample, data was collected daily throughout the study period. Due to an inability to assess demographics of Instagram users, we did not dichotomize the data into photographs of adults and children due to risk of error. Therefore, we did not differentiate between photos of children and those of adults in our study. Children do have FDA approval to wear the Dexcom® on the abdomen and buttocks, while adults only have FDA approval for the abdomen. In our study, photographs on the buttocks was nominal, however, considering the public nature of Instagram, this is understandable. Future work should make an effort to examine off-label use of CGM derived from survey and/or clinical research.

Conclusions

In this study we used photosurveillence to successfully identify real-world trends in CGM wear, including placement and length of wear. We found individuals successfully used CGM in off-label locations with greater frequency than the abdomen, with no indication of sensor failure or significant adverse effects. People with diabetes who are using CGM are finding ways to effectively use the tools in a manner that fits with their individual needs and goals, which is augmented by others on social media. Health care providers, industry, researchers and even the FDA may want to utilize photosurveillence as a method to discover how people are using diabetes technologies successfully in their daily lives and perhaps adjust care protocols or product design accordingly.

Acknowledgements

None.

Conflicts of Interest

None.
References


