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Using a health observance event to raise awareness: An assessment of World Birth Defects Day

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Abstract

World Birth Defects Day (WorldBDDay), observed annually on March 3, was launched in 2015 to advocate for public health surveillance, research, and prevention of birth defects, along with improved care and treatment for affected individuals. Following its fifth observance in 2019, we assessed WorldBDDay by analyzing: (a) engagement and content of over 2000 WorldBDDay posts on Facebook, Twitter, and Instagram; (b) interview responses from 9 WorldBDDay charter (founding) organizations on their perceptions of strengths and areas for improvement for WorldBDDay; (c) survey responses from 61 WorldBDDay 2019 partner (participating) organizations on their WorldBDDay 2019 activities; and (d) post-2019 social media engagement. Most social media posts (60%) occurred from organizations using Twitter (80% vs. 14% for

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Instagram and 6% for Facebook), although posts from individuals had higher levels of engagement (e.g., likes and comments). The highest engagement occurred for posts focused on general awareness, prevention, or events. Charter organizations reported the need for existing and new partner engagement, including a designated WorldBDDay contact for regular communication and coordination of activities and prepared prevention-focused messaging. Partner organizations reported using the WorldBDDay toolkit, especially key messages and social media tips, and suggested expanding the toolkit with relevant resources. Post-2019 Twitter engagement was lower than 2019 WorldBDDay (peak event) but showed similar reach to WorldBDDay events prior to 2019. Our assessment identified WorldBDDay health observance events as an important tool to support knowledge dissemination and global community engagement around birth defects. Moving forward, engagement with more individuals and organizations may improve the reach of WorldBDDay.

Keywords

awareness day; birth defects; evaluation; health awareness day; health promotion; social media

1 | INTRODUCTION

Each year, an estimated 3%–6% of babies worldwide are born with a serious birth defect (also known as a congenital anomaly or malformation), with over 90% of these births occurring in low-and middle-income countries (Christianson et al., 2009). Children born with a birth defect are at increased risk for early mortality and life-long morbidity. About one-third die before age 5, and another one-third live with a significant disability (Groisman et al., 2019). Although the causes of many birth defects remain unknown, effective prevention strategies exist for several conditions. For example, many neural tube defects (NTDs), severe birth defects of the brain and spine, can be prevented by maternal periconceptional intake of 400 mcg of folic acid daily (Berry et al., 1999). A recent study estimated that in 2019, about 280,000 cases of NTDs could have been prevented with sufficient folic acid intake (Kancherla et al., 2021). Disability due to some birth defects can also be reduced by improving access to timely and effective care (Grimes et al., 2016).

Birth defects are a global health issue that impacts individuals and families of all races and nations. For example, mothers of children with congenital heart defects in Korea reported feeling shocked and worried (Im et al., 2018). Similarly, caregivers for children with cleft lip and palate and also spina bifida in South Africa said they felt stunned, anxious, sad, guilty, rejected by others, and in need of information upon receiving the birth defects diagnosis (Hlongwa & Rispel, 2018; Page & Coetzee, 2021). Middle school-aged children with cleft lip and/or palate across various countries were more likely to report being bullied than those without this birth defect (Ammar et al., 2020; Glener et al., 2017; Nahal et al., 2019).

Feelings of being isolated and overwhelmed are common among parents of children with birth defects, especially immediately following the diagnosis (Lemacks et al., 2013). Often, parents are interested in advocating for research efforts and communicating prevention strategies to prevent future parents and children from being affected by birth defects (Holm

et al., 2021; Lemacks et al., 2013). The need to connect these parents to professionals and organizations in the field of birth defects, and particularly the need to increase general awareness of birth defects and their consideration by local and global policymakers, motivated the International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR) and 11 other charter organizations in 2015 to establish World Birth Defects Day (WorldBDDay).

WorldBDDay is a global health observance event held annually on March 3 to raise awareness and action for birth defects surveillance, research, prevention, and care. Health observance events can be defined as "brief exposure, high visibility program[s] designed to stimulate thinking and discussion of certain health risks and issues by large numbers of [people] (Purtle & Roman, 2015)," and can be an effective health communication strategy in raising awareness about health topics (Owen & Youdan, 2006). The charter organizations envisioned WorldBDDay as a way to raise global awareness for birth defects and to leverage the power of a unified voice to promote increased surveillance, research, prevention, and care strategies in helping to change the lives of people living with birth defects (Groisman et al., 2019; WBDD Charter Document—World Birth Defects Day, n.d.). The ICBDSR initiated WorldBDDay and greatly expanded the partner network through their connections, social media engagements, and annual conference. By February 2020, the number of partner organizations participating in WorldBDDay had increased to 191 organizations, with 31% from Europe, 31% from the Americas, 20% from Southeast Asia, 6% from the Eastern Mediterranean, 6% from Africa, and 4% from the Western Pacific (Map—World Birth Defects Day, n.d.).

The WorldBDDay charter organizations recognized that the use of social media was a powerful and low-cost approach to connect organizations and individuals globally and to inform and educate policymakers and other relevant organizations. As such, they chose to focus on Facebook, Twitter, and Instagram as the primary social media methods of information dissemination to help maximize the impact of WorldBDDay. Facebook is commonly used in the health field due to its nearly three billion active users each month and its ability to reach diverse populations (Alonso-Cañadas et al., 2020; Facebook MAU Worldwide, 2022). Twitter is also commonly used to disseminate short health messages and has over 300 million active users (Muralidhara & Paul, 2018; Thackeray et al., 2013). Instagram is an image-based platform with nearly 1.3 billion users (Instagram Users Worldwide 2025, n.d.; Muralidhara & Paul, 2018). WorldBDDay is a volunteer-led effort, with coordination through an ad-hoc ICBDSR group that brings together interested partners to coordinate events and develop WorldBDDay educational messages and a social media toolkit. WorldBDDay partner organizations were encouraged to create social media accounts, follow other WorldBDDay partner organizations on social media, use messages published on the WorldBDDay official website, and include information about WorldBDDay on their organizational websites. These organizations were also encouraged to host an awareness-raising local activity for WorldBDDay, such as a health seminar or policy discussion.

Following its fifth observance in 2019, WorldBDDay charter organizations identified a need to evaluate the event to identify any successes and areas for improvement for future

observances. As such, we sought to assess the reach of WorldBDDay that year by examining the social media and partner engagement with the health promotion strategies and messages utilized, which could identify areas of improvement for future health observance events. Additionally, we continued to assess general social media use following 2019 in order to analyze major trends and patterns beyond this prominent year.

2 | MATERIALS AND METHODS

Our assessment of the WorldBDDay 2019 health observance event was conducted in three phases. First, we identified social media posts on Facebook, Instagram, and Twitter related to WorldBDDay from May 1, 2018 to April 30, 2019 that included at least one of five main hashtags: #WorldBDDay, #WorldBirthDefectsDay, #ManyBirthDefects1Voice, #DiaMundialDefectosCongenitos, and #MuchosDefectosCongenitos1Voz. The searches used to identify these posts were conducted twice to minimize missed messages. In addition to the post content, other information gathered included the account name, number of followers, date, post content, and post language. Descriptive statistics were calculated using Excel. Additional analyses of the number of followers and the number of people viewing and engaging with social media posts were provided by free analytical software from Facebook and Twitter. Instagram posts were analyzed using a free version of the Squarelovin tool, which allowed for posts to be captured over a longer time period than Instagram's built-in analytics. The average number of engagements per post was calculated by dividing the total number of engagements (likes, comments, shares/retweets, and mentions) by the number of posts in a category to compare the level of engagement across categories and platforms.

The second phase entailed structured interviews with nine individuals from eight charter organizations to gather responses about what worked well and what could be improved from WorldBDDay 2019. These nine individuals have been involved in leadership positions with some of the charter organizations since the inception of WorldBDDay. When possible, recordings of the interviews were made and transcribed, with files kept on a password-protected device and deleted after project completion. A list of qualitative codes was developed by the interviewer, who then used the information to manually annotate transcriptions and identify consistent themes. The codebook included deductive codes from the interview guide and inductive codes that emerged during the interview process. Example codes included collaboration, country-specific promotion, and recommendations.

The third phase included a feedback survey (in English and Spanish) sent to the 191 WorldBDDay 2019 partner organizations. Descriptive statistics summarizing the survey responses were calculated using Excel. Also, open-ended responses were summarized and grouped into common themes.

In addition, the impact of social media efforts for WorldBDDay beyond 2019 was monitored using Sprout Social.

3 | RESULTS

3.1 | Social media

All types of organizations combined accounted for 61% of the 2042 posts identified, compared to individuals (39%) (Figure 1). However, individuals had higher levels of engagement per post (number of likes, comments, mentions, retweets, and shares) than organizations across platforms. Across platforms, most (41%) of social media accounts had 500–4999 followers, followed by 100–499 followers (26%), 26–99 followers (12%), 10000 and greater followers (10%), less than 25 followers (5%), 5000–9999 followers (3%), and an unknown amount of followers (3%). The types of organizations, governments, networks/alliances, or non-governmental organizations who posted were those that provide support for individuals and families affected by birth defects. Across platforms, organizations whose posts had higher engagement per post included governments, hospitals, and support organizations.

Most posts identified occurred on Twitter (80%), followed by Instagram (14%), and Facebook (6%). Similarly, among these social media platforms, Twitter had the greatest number of accounts engaged, with 249 accounts posting about WorldBDDay, compared to 97 Instagram and 40 Facebook accounts. Accounts that had posted information were based around the world, with 43% from the Americas, 18% from Europe, 6% from Africa, 6% from the Western Pacific, 6% multinational, 5% from Eastern Mediterranean, and 2% from Southeast Asia. Fourteen percent of posts were from an unknown location.

Across platforms, most post content is related to general awareness, prevention, and events. On Instagram, general awareness was frequently discussed (55% of Instagram posts, 45% of tweets, and 38% of Facebook posts); whereas prevention was mentioned often on Twitter (32% of tweets, 17% of Facebook posts, and 14% of Instagram posts), and events were frequently promoted on Facebook (27% of Facebook posts; 19% of tweets; and 14% of Instagram posts). The average number of engagements by type of post ranged from 3 to 53, with the highest engagement occurring when posts focused on general awareness or condition-specific information (Figure 2). Overall, most posts across platforms were in English (48%–64%), followed by Spanish (25%–30%), bilingual posts (10%–20%), and those in another language (1.5%–7%).

On Facebook, activity related to the WorldBDDay account (number of accounts following the page and post reach) increased in December as the number of posts increased, and again from mid-February through mid-March. Similarly, peak activity on Instagram occurred during the month before WorldBDDay. On Twitter, the greatest activity occurred on WorldBDDay (March 3).

3.2 | Individual interviews with charter organizations

Specific themes that emerged from the nine interviews with individuals from charter organizations included the: (1) need to expand the event's reach; (2) need for a designated central contact for regular communication for all partner organizations; (3) importance of collaboration between partner organizations when planning; (4) importance of prevention-

focused messaging; and (5) Twitter Chat's success in uniting those working in the field currently and the challenges of including new partners.

Most interview respondents discussed the need to improve the reach of WorldBDDay. One respondent suggested, “having pamphlets or programs that are not too technical to reach out to normal folk who are not too tech savvy or the rural areas or people who are not that connected to the grid.” The respondent also commented that “all the countries that participated are probably really doing well in terms of prevention and care, but the countries/regions that are still not completely in with fortification, prevention programs, vaccinations, those would benefit from understanding better about birth defects and seeing the global community of birth defects.” A second respondent commented, “Maybe an approach would be to find somebody who's got a real following on social media and get them to blog about or comment on [WorldBDDay].” This respondent also commented that “the big challenge is reaching out to people beyond the partners who are already engaged.” A third respondent suggested that “if we want to increase the number of partners everywhere in the world, we need to encourage personal contacts between partners in present organizations and others.” Most respondents also discussed communication related to WorldBDDay. Statements from positive responses focused on the regular newsletter updates sent to partner organizations. For example, one respondent stated, “The newsletter is good for communication directly to partners. […] I think it's important to have a contact person for the participating organizations [and] to have a way of communicating with them throughout the year, not only the month before to try to have contact with them and learn about what they are doing.” Positive comments also focused on the social media workgroup. One respondent stated, “a group call once in a while […] got more commitment to participate.” Suggestions for improvement included providing information to partner organizations through Twitter and the WorldBDDay website, clarifying leadership roles, and ensuring that all relevant individuals from each organization are receiving the information. For example, in larger organizations, sometimes only one contact would receive the information and would not pass it along to other team members participating in WorldBDDay. Respondents suggested that preparation for WorldBDDay begin about 4 months in advance, with a pause over the holidays, to allow time for partner engagement and sufficient planning of events.

Prevention messaging was another common theme discussed by respondents. One respondent commented that a “very important thing we can do on this day is to remove any misconceptions people might have. […] Maybe have very clear messaging for things that may stop people from taking active steps towards prevention.” Another respondent commented that “using images with a short message on prevention was really effective.” A third respondent commented, “The final aim of WorldBDDay should be to change the reality by making available the knowledge for prevention and for care everywhere in the world.”

The Twitter Chat, which was a new addition to WorldBDDay 2019, was mentioned by several respondents. One respondent stated that “the groups came together very well, at least for the Twitter Chat. Everyone brought their own expertise, and it was so smooth and ran like a really well-maintained machine.” However, two respondents noted that Twitter Chat participants typically are only from the groups that organized the Chat, rather than reaching a new broader audience.

Although it did not arise to the level of a theme, one respondent also mentioned the importance of providing materials in at least English and Spanish, and the need for local areas to have materials available in their languages.

3.3 | Survey of partner organizations for WorldBDDay 2019

Seventy-two percent of partner organizations who responded completed the English survey and 28% completed the Spanish survey. Sixty-one of the 191 (32%) WorldBDDay partner organizations responded to the online survey, representing 30 countries. These organizations tended to be surveillance programs (28%), governmental (27%) or non-governmental (27%) organizations, and universities (17%). Fourty-seven percent of organizations worked at the national level. Thirty-six percent of organizations that responded indicated that they have participated in WorldBDDay since its inception, and 28% stated that they just joined the event in 2019. The most common methods for recruiting partner organizations to support WorldBDDay came from the ICBDSR newsletter (30%), networking (22%), other methods (22%), or personal contacts (20%). Only 14% of respondents indicated learning about WorldBDDay through social media.

Top WorldBDDay 2019 activities conducted by partner organizations included: WorldBDDay content on partner organizations' websites (67%), Facebook posts (64%), hosting a local activity (58%), or Twitter posts (47%). Organizations were more likely to have Facebook (73%), than Twitter (65%) or Instagram (25%). Some organizations also used WhatsApp, Telegram, or Yahoo to promote their messages. Among organizations reporting having a social media account, most (41%) reported having 500–4999 followers, followed by 100–499 followers (25%), 10000 and greater followers (11%), 26–99 followers (10%), 500–9999 followers (7%), and less than 25 followers (5%).

Most (64%) organizations preferred to begin the promotion of WorldBDDay in December or January, which is about 2–3 months before the event. The WorldBDDay toolkit was the most common resource used by participating partner organizations. Specifically, many used WorldBDDay's logo (83%), key messages (61%), social media posts/tips (48%), and a presentation on WorldBDDay (47%). Respondents suggested adding a repository of materials for organizations to use and adding videos, more information on specific birth defects, and more local languages.

3.4 | Post-2019 Twitter social media assessment

Based on a Twitter WorldBDDay hashtag analysis over the last 5 years, WorldBDDay 2019 had the largest volume of original tweets and retweets (Figure 3). This analysis included both original posts and retweets containing #WorldBDDay, #ManyBirthDefects1Voice, #DiaMundialDefectosCongenitos, and #MuchosDefectosCongenitos1Voz. Although #WorldBDDay remained the most used hashtag, the secondary #ManyBirthDefects1Voice hashtag decreased in use in 2021 and 2022.

3.5 | Data triangulation

Table 1 provides a summary of results across the three data collection methods: Social media, individual interviews with charter organizations, and the survey of organizations for WorldBDDay 2019.

4 | DISCUSSION

Currently, published literature evaluating health observance events is sparse. This assessment adds to the body of literature through its assessment and mixed methods approach. Our assessment of WorldBDDay 2019 showed that this health observance event connected organizations from around the world and engaged social media users by providing information on general awareness and condition-specific information on birth defects. This awareness day was also an inexpensive way to share resources among these organizations and with the general public. We observed that WorldBDDay 2019 engaged more organizations than individuals (61% vs. 39%) on social media. By comparison, tweets related to Breast Cancer Awareness Month in 2012 more often came from individuals than organizations (93% vs. 7%) (Thackeray et al., 2013). This difference may be due in part to the management of each event. As WorldBDDay was being formed, it was promoted through organizational networking, engagement with World Health Organization regional offices, and through ICBDSR, which is comprised of member birth defect surveillance programs. Also, there may be more unity in the breast cancer community, whereas people are often siloed into focusing on a specific birth defects rather than all birth defects as a group. The length of the awareness event (1 day vs. 1 month) may also affect who participates. Organizations may be more likely to participate in a one-day event than engaging over an entire month.

A summary of identified needs and recommendations is provided in Table 2. One common theme across our mixed methods of data collection was that, judging by posting and post-sharing patterns, WorldBDDay appeared to engage primarily organizations already working in the birth defects field rather than expanding awareness among the general public. This concern was also voiced during interviews with individuals from charter organizations, indicating a need for new ways to educate current and potential collaborators, and to evaluate the impact of WorldBDDay on general awareness. Suggestions from interview respondents on how to engage the public included connecting with WhatsApp groups and engaging young celebrities in the cause.

Our evaluation of social media posts showed that Twitter had higher WorldBDDay engagement than Facebook or Instagram. This finding may have been due to the nature of Twitter involving frequent tweeting and retweeting of short messages. Another reason may be that a WorldBDDay leader promoted Twitter at an ICBDSR meeting where many WorldBDDay partner organizations were in attendance. At this meeting, the leader also offered a training and helped organizations sign up for Twitter. Lastly, the Twitter Chat event may have increased engagement on Twitter both before and after the event. However, the survey of partner organizations identified that organizations were most likely to have Facebook, followed by Twitter and Instagram.

WorldBDDay activity varied over time. Across data sources, it was clear that participants wanted to increase engagement a few months ahead of WorldBDDay, with the greatest effort culminating on WorldBDDay. On Facebook, social media activity related to the WorldBDDay account increased in December, and again from mid-February through mid-March, which corresponds to the period immediately before and after WorldBDDay. Similarly, peak activity on Instagram occurred during the month before WorldBDDay. On Twitter, the greatest activity occurred on WorldBDDay (March 3).

We also observed that many social media posts related to WorldBDDay 2019 focused on general awareness, prevention, and WorldBDDay events. These results are consistent with analyses of tweets for Breast Cancer Awareness Month, World Autism Awareness Day, and World AIDS Day (Karusala et al., 2019; Thackeray et al., 2013). Tweets related to those awareness events focused on fundraisers, events, early detection, organizational efforts, and condition-specific information.

A study of World Autism Awareness Day and World AIDS Day compared message content between India and the U.S. and reported that the U.S. focused more on centralized awareness strategies on a national level, whereas India was more likely to use decentralized awareness strategies focused at the community level (Karusala et al., 2019). This aligns with comments of one charter organization interview respondent that many regions with the highest burden of birth defects may be poor and/or rural, which may limit their access to social media, the main method of sharing messages related to WorldBDDay. The respondent suggested that WorldBDDay involve other large organizations with experience working with rural and/or poor populations to reach those with limited access. Another interview respondent suggested having regional champions and leaders who could help tailor messages to more narrow cultural contexts. These regional leaders could help meet the expressed desire of surveyed partner organizations to have resources translated into more languages. Future assessments of WorldBDDay should identify geographical differences in the messaging being utilized and the information needed by the general public to maximize cultural relevance and impact.

Interviews with individuals from charter organizations revealed that prevention is considered important, but reduction of stigma through personal stories is also potentially impactful. This two-fold method can help to prevent birth defects from occurring, while reducing stigma and its impacts on those who are affected by birth defects. Similarly, tweets about World AIDS Day focused on prevention and testing, whereas tweets about World Autism Awareness Day focused on reducing stigma for affected individuals, sharing personal stories, and recognizing the impact on family members and society (Karusala et al., 2019).

WorldBDDay's goals to fight stigma and provide information are also shared by International Overdose Awareness Day (IOAD) (Partners Report 2018, 2019). A comparison of surveyed individuals from both WorldBDDay and IOAD supported a similar sense of community shared by those who participated (Partners Report 2018, 2019). This comparison of responses by WorldBDDay participants and IOAD stakeholders further recommended increasing partner engagement and commitment as well as access to a repository of prepared materials, including photos, for people to use when promoting the day. Although social

media is a low-cost way to quickly spread messages, resources are still needed for websites, staff, and other planned events. Specifically, interview respondents identified a need for resources, such as clear messaging to use when promoting WorldBDDay, while survey respondents also suggested adding a repository of materials for organizations, such as videos, information on specific birth defects, and translations into local languages. A lack of resources, such as staff, can be a barrier to participation in lower-income areas, where individuals and organizations may lack resources to participate in awareness activities through social media. This may have contributed to lower participation in some regions, such as Africa, despite a high burden of birth defects in those regions.

The number of WorldBDDay partners grew over the past 5 years from 12 to 191 organizations; however, in both interviews and surveys, respondents frequently mentioned a need to increase reach and the number of partner organizations. Engaging individuals and organizations involved in reproductive, maternal, newborn, and child and adolescent health or nutrition; other health awareness days; local ministries of health; and large global organizations, could help boost WorldBDDay awareness and promotion. The emergence of two seemingly opposing themes, one that WorldBDDay should seek to engage more individuals rather than organizations, and that WorldBDDay needs to expand its number and type of partner organizations, may indicate two separate beliefs on the best methods to increasing awareness. However, these themes are not necessarily incompatible as both methods may increase awareness by reaching different populations.

Our WorldBDDay 2019 assessment has some potential limitations. One limitation was that all interviews were conducted in English with individuals from charter organizations, and the survey with WorldBDDay partner organizations was only available in English or Spanish. Although both languages were the primary languages used for WorldBDDay materials and resources, individuals with limited proficiency in either language may not have participated due to a language barrier. Another limitation was that WorldBDDay was developed using limited funding, with most work being performed on a volunteer basis. As WorldBDDay grows, support to expand infrastructure may help facilitate additional activities, such as active support for family/patient organizations and including translating WorldBDDay resources into additional languages so that worldwide participation and influence may grow. A third limitation was identifying posts related to WorldBDDay 2019 using five hashtags. Posts that did not use these hashtags may have been missed, which may have underestimated the reach of WorldBDDay 2019. Additionally, only original posts were included given that identifying all shares and retweets is difficult. Despite these limitations, the results provide insights into successes and areas for improvement related to social media-based health awareness days.

Since 2019, WorldBDDay has continued to promote the global day with similar events, such as the Twitter Chat and other local events across the globe, engaging both individuals and partner organizations. One important factor to consider in the recent promotion of WorldBDDay is the COVID-19 pandemic. Despite the global disruption of the COVID-19 pandemic following March 2020, both the use of and dependence on social media platforms to stay connected drastically increased during this time (Wong et al., 2021). The increased use of social media during the COVID-19 pandemic may support increased engagement

in future WorldBDDay events. A study conducted in 2020 reported an average 50%–70% increase in internet use among Americans, with one-half of their time spent on social media platforms (Beech, n.d.). In addition, Twitter was identified as the leading social media platform for COVID-19 related information during the pandemic (Tsao et al., 2021). Therefore, during the pandemic, Twitter and other platforms were being inundated with COVID-19 related information, which likely drew attention and participation away from our post-2019 WorldBDDay campaigns. This dependence on social media during the pandemic has entirely shifted the health communication environment, as individuals and organizations are now tasked with using their social media platforms to generate, communicate, and disseminate both accessible and accurate information to their audiences (Wong et al., 2021). In response to the pandemic, different communication strategies have been recommended and are highly encouraged to be adopted by future WorldBDDay campaigns, such as: using narratives, engaging risk communication professionals, acknowledging uncertainty, tailoring information to local levels, and providing regular ongoing two-way communications (Gesser-Edelsburg, 2021).

5 | CONCLUSIONS

WorldBDDay as a health observance day serves as an important vehicle to galvanize organizations and individuals toward promotion of global birth defects awareness, prevention, and care. In the 2019 event, support organizations were particularly successful in social media engagement through Twitter, peaking on WorldBDDay. Interviewed individuals from charter organizations valued these communication strategies and suggested strengthening the organization of the event and expanding the number of communication channels. Individuals from charter organizations and social media messaging both considered prevention messaging to be an important facet of WorldBDDay. Based on the success of this health observance day and the lessons learned through the evaluation, the WorldBDDay workgroup plans to expand and enhance future WorldBDDay events to increase awareness and engagement with more individuals and organizations to promote better prevention and care for individuals, families, and communities affected by birth defects.

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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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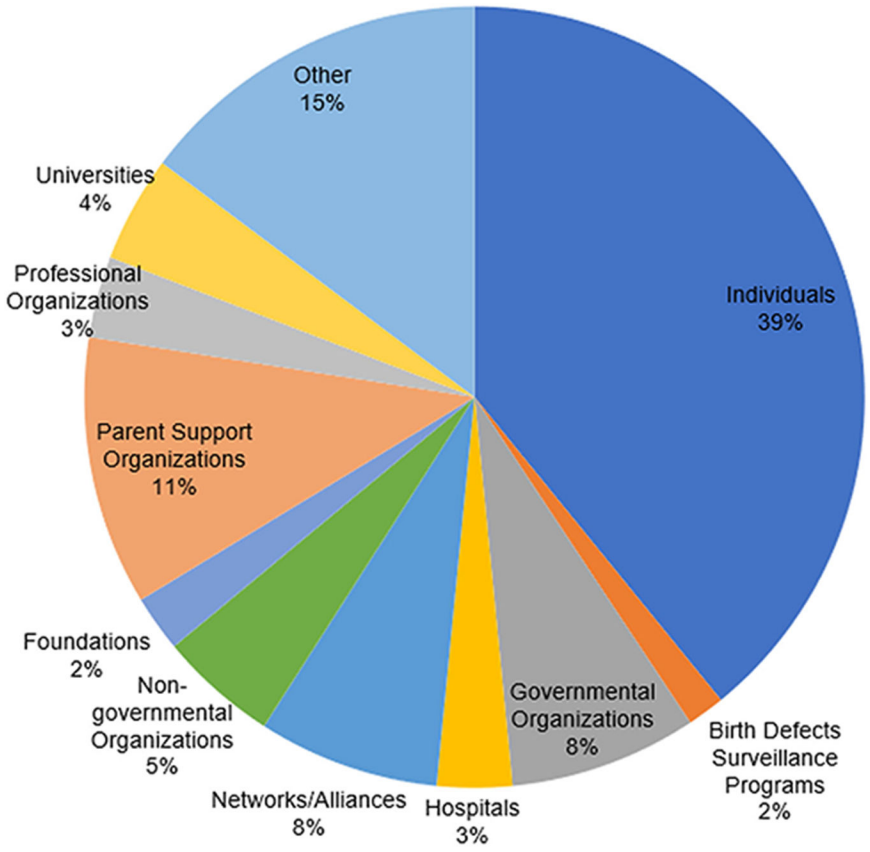

FIGURE 1.
Types of groups who posted WorldBDDay social media messages.

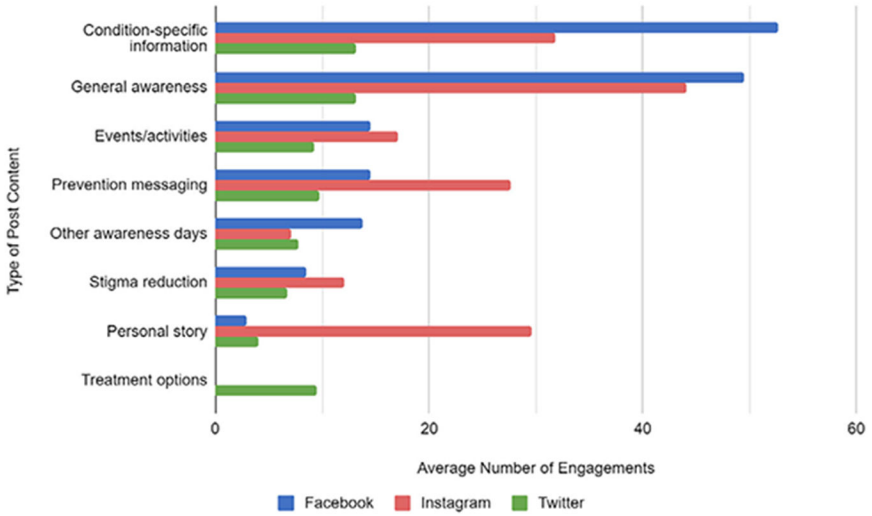

FIGURE 2.
Average engagement per post across three social media platforms.

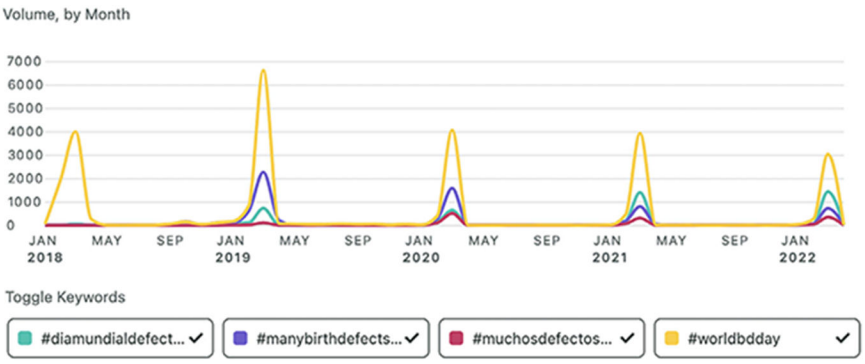

FIGURE 3.
Analysis of WorldBDDay Twitter hashtag use between January 1, 2018 and April 19, 2022.

TABLE 1

Data results triangulation.

Topic	Social media	Individual interviews with charter organizations	Survey of partner organizations for WorldBDDay 2019
Individual versus organizational participation	Individuals had higher levels of engagement per post than organizations.	Suggested engaging with a social media influencer.	None
Organizational type	Organizational accounts who posted were primarily support (11%) and other (15%) organizations.	Identified a need to engage more, and a greater variety of, partners.	Identified a need to engage more, and a greater variety of, partners. Currently, most are non-governmental organizations (21%), birth defects surveillance programs (20%), and governmental organizations (19%).
Social media followers	Most accounts (41%) had 500–4999 followers.	N/A	Most accounts (41%) had 500–4999 followers.
Content	Most posts (46%) were about general awareness, followed by prevention messaging (28%).	Noted that prevention messaging is key.	N/A
Language	Most posts were in English (48%–64%), followed by Spanish (25%–30%), bilingual posts (10%–20%), and those in another language (1.5%–7%).	One respondent mentioned the importance of providing materials in at least English and Spanish, and the need for local areas to have materials available in their languages.	Respondents recommended having materials available in additional languages. Seventy-two percent of partners completed the English survey and 28% completed the Spanish survey.
Timing	Across social media platforms, activity was highest around WorldBDDay, with a clear increase before on Facebook and Instagram.	Suggested starting planning and early dissemination in the late fall, and slowly increasing promotion closer to WorldBDDay.	Most (55%) suggested beginning promotion in December/January.

TABLE 2

Summary of identified needs and recommendations.

Identified need arising from the results	Recommendation	Supporting data sources
WorldBDDay primarily engaged organizations already working in the birth defects field	• Educate current and potential collaborators • Evaluate the impact of WorldBDDay on general awareness • Connect with WhatsApp groups • Engage young celebrities in the cause • Engage individuals and organizations involved in reproductive, maternal, newborn, and child and adolescent health or nutrition; other health awareness days; local ministries of health; and large global organizations	Identified need • Social media • Individual interviews • Survey of partner organizations Recommendation • Individual interviews • Survey of partner organizations
Many regions with the highest burden of birth defects may be poor and/or rural, which may limit their access to social media, the main method of sharing messages related to WorldBDDay	• Involve other large organizations with experience working with rural and/or poor populations to reach those with limited access • Create regional champions and leaders who can help tailor messages to more narrow cultural contexts • Future assessments should identify geographical differences in the messaging being utilized and the information needed by the general public	Identified need • Individual interviews • Survey of partner organizations Recommendation • Individual interviews • Survey of partner organizations
Desire for additional resources	• Develop a repository of prepared materials, including photos, for people to use when promoting the day • Provide additional resources, such as staff and volunteers, to support promotion of the day	Identified need • Individual interviews • Survey of partner organizations Recommendation • Individual interviews • Survey of partner organizations