

The Pandemic as a Stimulus for Innovation in Pediatric Cancer Care

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Abstract

What is the message? The paper serves as a case study of COVID-19-related innovation in pediatric cancer care services. The pandemic promoted the Pablove Foundation to revamp and expand its Pablove Shutterbugs Photography Program, an artistic outlet for pediatric cancer patients.

What is the evidence? The authors draw on their experience with Pablove Foundation and other relevant organizations.

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The Pandemic Can Stimulate Innovation in Pediatric Cancer Care

The harsh reality of COVID- 19's withering impact on society is well-documented and justifiably

feared. Like many complex problems, diverse perspectives exist regarding how to approach the virus and minimize its adverse effects. This paper examines the perhaps unsettling perspective of the pandemic's upside for healthcare delivery — opportunities for innovation. It is possible to reframe society's struggle with the virus and explore COVID-19 as a stimulus for disruptive innovation.

COVID-19's propensity to stimulate innovation surfaced in The Pablove Foundation (hereafter the Foundation), an organization working closely with medical groups and healthcare providers treating pediatric cancer patients. Headquartered in Los Angeles, with six additional program sites across the United States, the Foundation grappled with COVID-19's sweeping impact. The virus not only caused a seismic shift in the Foundation's patient care and research programs, but it also underscored the importance of maintaining a closely knit, and scalable, clinical network. In such a network, information can be rapidly shared, innovations nurtured, new protocols vetted for pilot testing, continuous evaluation undertaken, and agility fostered in both the organization and among its constituents (i.e., managers, physicians, scientists, volunteers, staff and patients). Most importantly, the Foundation and its partners remained agile in an ambiguous care delivery environment focused on highly vulnerable children with cancer.

Passages of Innovation

In the United States, approximately 11,050 children under the age of 15 are estimated by the American Cancer Society to be diagnosed with cancer.¹ This represents 11,050 families that will bear the burden of navigating cancer's potential lasting physical, cognitive, and psychological effects on their children.² Pediatric cancer is the second leading cause of death in children under the age of 15. In addition to these medical realities, families face the economic burden of an estimated expense of \$833,000 per child, including medical costs and lost parental wages.³ These facts paint a vivid picture of the disheartening medical and economic toll that pediatric cancer continues to take on U.S. families.

The Foundation was established through a broad base of private donations and focuses on two objectives: 1) improving the quality of life for pediatric cancer patients through art, while physicians, allied clinicians, and partnering medical groups try to work their clinical magic, and 2) investing in high-pay-off pediatric cancer research focused on eradicating cancer and providing better treatment options. This paper focuses on the quality-of-life objective uniquely

embraced by the Foundation.

Pablo's Story

The Foundation was founded 2008 in reaction to the horrifying words, “Your child has cancer”, and the story of a young boy, his family, and his community. Pablo’s parents endured a 13-month roller coaster when their five-year-old son was diagnosed with bilateral Wilms Tumor, a rare childhood cancer. Despite an aggressive treatment regime and intensive collective efforts by the medical community, Pablo lost his battle with cancer only six days after his sixth birthday. In the following weeks, his parents continued to find photos Pablo had taken with their smart phones and other equipment.

Pablo’s parents reached an important realization after his passing. Photography had enabled Pablo to chronicle and document inspiring moments of his life, as well as to record his love of his family through an abundance of family portraits. Looking back over the exhausting experience, his parents began to wonder whether other children and parents could benefit from a similar artistic respite.

The Pablove Shutterbugs Photography Program

Inspired by the retrospective understanding of Pablo’s experience, the Pablove Shutterbugs Photography Program (PSPP) was created within the Foundation in 2011. This program offers children living with cancer an opportunity to “develop their creative voice through the art of photography” while interacting with a master teaching artist and a community of other children. In this respect, PSPP programming is uniquely designed to foster participatory arts. Children living with cancer have the opportunity to re-identify with a subject beyond the context of cancer. They seek respite, joy, self-esteem, courage, creativity, identity, voice, learning and achievement beyond their cancer. By living largely beyond the looming stigma as cancer victims, they can envision a new normality where they are not solely defined by the disease, where a kid can be a kid again.

Interest from other U.S. communities led to a second innovation: a national expansion to accommodate the PSPP. The Foundation expanded from Los Angeles, home of its administrative headquarters, to new program sites in Houston, New York, Seattle, New Orleans, Boston, and

San Francisco. The PSPP's impressive quality-of-life dimensions became accessible to other children, while at the same time galvanizing a national community.

COVID-19 as a Catalyst for Disruptive Innovation

With the many restrictions imposed by COVID-19, the Foundation experienced a decreased ability to assist physicians, their medical groups, and pediatric cancer patients. Nothing about the COVID-19 experience suggested that the Foundation would see anything other than detrimental impacts on its clinical care delivery programs and research. The virus loomed as a potential constraint that the Foundation could not overcome in its efforts to help children and their families cope with cancer during a pandemic.

Twenty-five years ago, Bower and Christensen (1995) captured the essence of innovations that entirely transform products and services via the term "disruptive innovation."⁴ Originally, disruptive innovations were defined as rudimentary or simple improvements that replaced more sophisticated or technologically complex products/services. Disruptive innovations gained fame as low-cost, but efficacious, substitutes. Eventually, disruptive innovation broadly opened what previously had been relatively narrow markets. Innovative low-cost products/services substantially broadened market share and gradually became dominant leaders. Illustrative instances of disruptive innovation include retail medical clinics, personal computers, and digital photography, among many others.

Although COVID-19 is neither a product nor service, it is a distinct causal factor that overturns traditional thinking about organizing and delivering medical products and services. Revisions in medical practice protocols, care delivery guidelines, and ancillary/supporting services due to COVID-19 are, in some cases, game-changing. Innovation is a necessary adaptation that allows traditional care practice and delivery to continue. Most adaptations begin as a conscientious effort to fine-tune and adapt an existing way of doing things. However, clinical providers and their organizations quickly realize that altogether more creative protocols and practices are essential in responding to the disrupter – for example, the COVID-19 virus and its variants – and thus grander innovation is spurred.

Disruptive Innovation in the Pablove Program Fueled by COVID-19

The public health challenges of the COVID-19 pandemic prompted the Pablove Shutterbug Photography Program to grind to a halt. The provider team paused to consider the best path forward given that every child participating in the PSPP program was at very high risk for infection. This hiatus led to lengthy discussions by staff, advisory board members, volunteers, clinicians, and participants (and their families). They debated whether an overabundance of caution should be used in scheduling further programming. In some respects, this appeared to be little more than stalling, hopefully waiting for the COVID-19 outbreak to be resolved so that PSPP programming could resume.

Limitations of Waiting as a Patina of Prudent Deliberation

Over time, it became increasingly difficult to square inaction with the general ethos of the Foundation: respite, hope, joy, and development of the creative voice of kids living with cancer. These cornerstones were believed more necessary during the pandemic than ever before. How to assemble a new and functional PSPP, despite the constraints, became the challenge. Additionally, the successive iterations of “new normal” definitions for life during the COVID-19 pandemic signaled that it was truly time to thoroughly re-engineer PSPP or otherwise admit defeat.

Ultimately a brainstorming session by the leadership team made an exponential leap in envisioning an entirely new hybrid PSPP that would be: 1) on par with its ambitious mission; 2) consistent with the constraints of highly vulnerable kids; and 3) lofty enough to transform the PSPP into an altogether next-generation version. This open mindset encouraged the team to think out of the box while pursuing alignment within the Pablove community of patients, providers, and staff.

In effect, COVID-19 gave the Foundation license to be more aggressive in rebuilding what had been an elegant and safe way to provide services for highly vulnerable children. The traditional face-to-face model was sidelined as a virtual model arose as a replacement. This sort of fresh thinking has become prevalent practice across many venues. COVID-19 became the disruptive causal factor for change. A unique twist for the Foundation was realizing that a missing subset of inpatients – children with cancer who must remain within institutional care could now be easily integrated, as could children and teens living outside the reach of the established program sites.

Initial evidence indicates that a virtual format in 2020, 2021, and 2022 (normalized to account for partial years) resulted in average annual participation enrollment of 237 children as compared to average annual participant enrollment of 201 children in 2017, 2018, and 2019 with in-person delivery. In part, higher enrollment in 2020, 2021, and 2022 is explained by the greater safety of virtual delivery to immune-compromised children as well as the ability of all seven Pablove sites to offer virtual delivery. Higher enrollment driven by virtual class delivery is also expected to increase total overall enrollment when in-person classes are reinstituted.

The Foundation had been talking for years about a virtual program, but rather than moving from intention to action, there was no pressing need to upset a functioning system of programming. Further, at full capacity, “being busy” stood in the way of disruptive innovation. COVID-19 nudged the Foundation forward, and as leaders came on board, fresh perspectives emerged on how the virtual model could overcome the at times cumbersome structure of face-to-face instruction. Perhaps more importantly, a vision of enhanced scalability underscored this innovation. Going virtual would allow multiples of children to be reached and cared for while maintaining an equally intimate relationship with master teaching artists that characterized the traditional PSPP delivery.

Reflecting on the dynamic shift in perspective and implementation of a broadly redefined pedagogy, the Foundation compared its progress with that of other medical providers who were unable to rise above the stable, but now insufficient, models they had always followed. Many medical and healthcare providers and their organizations inadvertently avoid change — usually with the wish and a prayer that things would once again return to normal. As the nation struggled with the distribution of vaccines, increased access to testing, and the development of new therapeutics, the Foundation realized that unless it moved toward a new model, its very existence was precarious.

Looking Forward

Observed through the evolution of the Foundation, disruption led to an emergent need, which stimulated the integration of innovation. What started as a good idea has been transformed into an ever-evolving search to improve the quality of life for children with cancer, while sparking innovation in research that is imbued with high-payoff potential. In and of themselves, the Foundation’s passages of innovation are significant and noteworthy for changing the landscape

for medicine and healthcare organizations delivering pediatric cancer care. COVID-19 ushered in a new constraint that validated the search for ingenuity, while affirming an ever-deepening recognition that it is always possible to achieve new levels of innovation.

There are very robust implications for the healthcare community and patients due to the Foundation's adaptations to COVID-19. As novel infectious diseases emerge or historical ones reemerge, there is great risk that some clinicians, healthcare leaders, and their organizations might reduce their service scope and lose market share, or even possibly eliminate those services. Consider the vast shocks that have happened to the airline industry, long-term care, education, entertainment, hospitality, and so many other economic sectors.

Health and medical leaders are encouraged to remain vigilant about possibilities for disruptive innovations in how their organizations address likely future debilitating viral events or catastrophic forces that may arise in the future. This can be very difficult when teams of providers and ancillary staff are exhausted from day-to-day battles with an unrelenting enemy. But those expectations about cultivating a climate of optimism and nurturing opportunities to instill ingenious responses are all part-and-parcel of courageous and inspired leadership. COVID-19 will not be the last threatening challenge that we face. Thus, now is a perfect time to create a milieu of imaginative thinking and bold execution of clever strategies designed to move forward. This is an opportunity to infuse all care delivery organizations with a unique culture that is capable and confident in addressing the toughest problems.

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