Chasing Rainbows! Supporting Community in Pediatric Palliative Care with Digital Media

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OVERVIEW

The Rainbow Kids Palliative Care program is a consultation service of Intermountain Healthcare’s Primary Children’s Hospital available for any child with a potentially life-limiting condition. The team assists families, inpatient care teams, and providers in the community. The program provides access to palliative care for children from the 6-state catchment area served by the hospital, which is located in the western United States. Most children have a complex chronic condition while others suffer from an acute illness or injury. Many are from rural areas without close access to a pediatric hospital for acute care. The team receives about 200 referrals per year and follows patients throughout their lifespan.

Our team has seen that many of the families served, regardless of geography, feel isolated while going through their journey. Support is offered to families through a combination of new technologies and classic principles of palliative care. One key to building relationships is the team’s innovative use of digital media. This trend of digital engagement is growing in recognition within the medical literature. While many uses of social media have been dismissed as shallow or even isolating, deep connections have been made among families who have faced similar challenges.

In addition to its digital outreach, Rainbow Kids fosters in person connections within the hospital. Team members round on patients and families when the children are hospitalized for acute episodes, and families are given a chance to socialize with each other and the team over a free meal offered every Tuesday. These lunches foster a community where parents can connect, share practical information, celebrate successes, and comfort each other in times of heartbreaking. We have seen the in person and digital engagement enhance one another. Reminders for lunch are posted online to help parents find opportunities to see each other in person. Parents also use the parent lunch and online forum to build connections of their own. It is not uncommon for a parent whose child is hospitalized to set up coffee or dinner with others who are in the hospital at the same time.

The Rainbow Kids efforts at digital and in person community building help children and their families experience greater comfort, support and hope. This has been vital for those families who feel isolated while caring for a child with a life-limiting condition. “They are like my family” one parent commented. “I can voice my concerns without being judged,” another said.

In addition to the programs listed above, the Rainbow Kids Palliative Care team was recognized in their Circle of Life citation of honor for fostering collaboration between the University of Utah in Intermountain Healthcare, finding ways to support families and providers throughout the continuum of care, and building partnerships with community organizations.

SPECIFIC USE OF DIGITAL MEDIA

Facebook:
Legal/Privacy Issues: In collaboration with Primary Children’s legal and public relations teams, a Facebook page was developed in 2013. To protect privacy and foster a sense of safety for the families, the page is designated as “Secret”. This page will not show up in any search, nor will information parents post appear anywhere else in their Facebook profile.

Use: At the time of submission, the page has over 800 members, averaging more than 8 new members each month. 10% of the members live in rural areas of Utah, while 17% live in different states. Parents use this forum to ask each other questions, celebrate successes, grieve, and post helpful they find helpful. Many teams have expressed concern that such a page would lead to inappropriate posts or negative comments about providers. This has not been our experience. In the years that we have used this tool only a small handful of posts have been taken down. The main reason for taking posts down is that we don’t allow parents to post fundraising events or pages.

Polling and Surveys: Our team has also found that a robust response rate through Facebook polls. These have been used for informal information gathering, improvement projects, and providing examples of program benefit to administrative leadership.

“Facebook Live” Events: Recently, the team has enhanced its digital offerings to its community of families. Two Facebook live events were hosted that garnered over 500 views within days. One covered guardianship issues while the other was a “get to know you” interview with the program’s medical director.

Twitter and Instagram: In response to requests from families and trainees, the team created accounts on these popular social media platforms. We have found them much less useful compared with Facebook, but are still experimenting with their uses. Within a few months on each platform we have over 150 followers on each account.

Podcasting: Since the time of the initial submission for consideration by the Circle of Life, the team has been working on the first season of their podcast, “the Rainbow Connection”. This is a program directed to families who may be hearing about pediatric palliative care for the first time. The first 2 episodes of the podcast are currently distributed through Soundcloud, but the team is exploring opportunities for wider distribution.

SUMMARY

Digital communication tools like Facebook, Instagram, Twitter, and Podcasting should be employed by all palliative care teams looking to enhance engagement with families. Programs looking to support families have many potential tools at their disposal. Since 2013, social media has proven to be a valuable tool in healthcare in instances like sharing resources, taking the pulse of families’ experiences, providing family to family support, and providing education when families need it most. These tools work together with more traditional tools of palliative care.

Our team has found legal and logistical concerns to be overstated. By working closely with legal and public relations teams, teams can be sure that they use these tools well and to their greatest benefit. Although we have had success with the platforms listed above, every team and institution will likely learn individualized lessons on what works best for their scenario. As social media evolves and improves we are likely only at the beginning of opportunities to support communities in palliative care through person-centered technology.

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