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This article is available in Patient Experience Journal: https://pxjournal.org/journal/vol1/iss2/1
A gathering place for patient experience research: The power of community

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Abstract

In introducing Issue 2, we explore the power of community and its implications in shaping not only the purpose and intent of Patient Experience Journal, but of the patient experience movement itself. Community defined in this moment is simple, yet significant, the key being unity around common interest and its focus on ownership and participation. The idea of community bears great weight and has provided strong guidance and purpose for the work of experience excellence. It supports the goal of elevating the conversation, helps align the voices engaged and provides the space for listening, learning and impact.

Keywords

Patient experience, community, Patient Experience Journal

I alone cannot change the world, but I can cast a stone across the waters to create many ripples.

Mother Teresa

The Power of Community

When we first gathered an initial group of individuals interested in a potential journal for patient experience research, there was both great anticipation and also some clear angst. As an emerging field of focus in healthcare, moving beyond fad status to a policy motivated and consumer driven reality raised significant opportunities to provide a space for conversation, research and much-needed rigor.

As patient experience evolved from concept to an idea increasingly seen put into practice across healthcare settings globally, the implications of understanding its definition and impact, the populations its ideas and concepts could impact, the arenas in which it would have significance, and the outcomes it could influence, all became central questions. These are questions that move ideas from theoretical principles to rapidly expanding fields of study. It was this ripple, as offered in the quote from Mother Teresa, that created a solid, yet dynamic, foundation on which to grow not just a movement for action, but a call for greater understanding of the critical scholar-practitioner interface that could drive not only concepts to stretch or shift our thinking, but also tangible results that could have positive implications for healthcare organizations and the communities they serve.

This unspoken call stoked great reverberations that in just the last few years has seen meteoric climbs in awareness, rapid shifts in terminology and management focus, and the emergence of measures, both in policy and social frameworks, introducing new consequences to the healthcare conversation. It has caused some to rise to find their strengths, others to struggle in new waters and some to drift unsure of how to proceed. These individual circumstances return us to the roots of this very publication. In bringing together ideas, thinkers, research and practice, successes and misses, drivers and cautious actors and through the sharing of ideas, the constant asking of questions, the willingness to try and yes, sometimes fail, and the commitment to learn and share from these experiments, we create the potential for something bigger. In coming together in the virtual framework of such a publication as Patient Experience Journal (PXJ), whether conscious of it or not, we reinforce a critical idea – there is great power in community.

Community defined for us in this moment is simple, yet significant – a unified body of individuals who share common and especially professional interests scattered through larger society. The key here being unity around common interest and the intent of our work to create a space for those common interests to be explored, tested, challenged, stretched, polished and even institutionalized. Equally critical to this idea of community is its focus on ownership and participation. These are powerful words
when it comes to an idea as important as the experience of those in our healthcare systems or impacted by the decisions made therein. In unified common interest, with a sense of ownership and purposeful participation, we have begun to build a community that has growing and powerful potential.

While academe has pushed us to new edges of thinking, the implications of that work in patient experience is much more personal. It speaks to situations in which lives, sometimes vulnerable, can be impacted and it could be people we may never encounter personally. But we also realize it could be and very well may be a dear friend, a loved one or even our self.

It is here where the idea of community again bears great weight and has provided strong guidance and purpose for our work with PXJ. If our goal together is to elevate the conversation, to help align and centralize various voices and then create a space for listening, learning and impact, we must build it with a sense of and care for our personal and collective communities. It is with this mindset that we launched this publication and with the continuation of this thinking through which we have engaged an extensive editorial board, almost 150 authors and as many reviewers in this first year of publication. This is an important topic and a critical time in our global healthcare dialogue and it will take our growing community to ensure the conversation continues.

A Solid Bridge to Issue 2

As we look to the work so far and to this issue, I encourage you look back at what set the stage for this publication. Issue 1 offered us foundational constructs from defining patient experience to examining the place of patient experience in the overall healthcare conversation. The issue also stressed the global nature of this conversation and that while systems may operate under different structures, frameworks and financing, there is one fundamental truth that I have yet to see challenged in my engagement on this issue – in healthcare we are but human beings caring for human beings. Add in professional expertise and skill, sprinkle in fear and emotion, add a touch of economic pressures and then season to taste and we have a very hearty scenario that changes with every encounter. So while we may drive to consistency or even replicable knowledge, we will also live in a world challenged by the very variation found at the core of our humanity itself.

Issue 1 crossed global boundaries to find common opportunities and explore shared challenges, it offered personal reflections and practical application of ideas, all the while reinforcing the very power of community and the sharing of ideas found at its core. In just the first six months, articles from PXJ were downloaded over ten thousand times. These pieces showed up in classrooms and whitepapers, as citations and grounding for new research and impacted choices made in hospital units or practice exam rooms. This reinforces the broad reach PXJ will continue to strive for.

Issue 2 will continue to push us further in this direction with over 75 authors contributing to twenty articles and a range of themes including patient experience practices, a focus on measurement and various patient populations, the incorporation of thoughtful commentaries, patient and family voice and book reviews. The breadth of topics reinforce the wide range and impact that patient experience has in the healthcare market today from its influence on cancer patients in the United Kingdom to how selecting the right physicians can influence outcomes. We explore the impact of measures from the U.S. perspective of the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) and from the impact of measures in the Emergency Department in addressing equity in Canada. Practice considerations are also explored from the challenges of the widely accepted practice of rounding to the implementation of experience based design.

While this summary just scratches the surface of what is contained on the pages of Issue 2, my hope is this peaks your interest in the broad range of topics available at just the click of your mouse. More so, I hope it inspires you to consider what you are exploring, what questions you look to study, what practices you are testing and what ideas you can add to expanding the conversation on patient experience improvement.

A Call to Action and Contribution

With that, I would be remiss in not inviting and actively encouraging you to consider where you have the opportunity to contribute. If we stand on the premise with which I started, that it is in the power of community, our common interest, ownership and contribution through which we can accomplish increasingly greater things for this movement and this field, then we must consider how we each contribute. While it may not be in extensive research efforts, what are you doing to impact the experience of care, what outcomes are you driving and what are you ready to share? Or how can you use any of the articles you may find in PXJ as a means to make change in your thinking, your practice or the way in which your organization takes action? Where can you also begin to create opportunities for shared learning in using this content for personal or professional development, in reading circles or even on your iPad or Kindle at night? How might you even challenge what you read, push us as an editorial team to stretch our work or where should we go in guiding the journal as we continue to expand the community and the conversation?
Underlying each one of those questions is an intentional call to action. Our purpose is not to invite you to publish simply for the sake of building your CV (though a perk), but rather and I would say I have seen this in every submission selected, there is a purposeful focus that broader contributions are to be made, lessons to be learned and new ideas yet to be discovered. We invite and encourage you to think about how you can do that on these very pages. As I stressed, PXJ is also going to be shaped by the very community it serves. In doing so, and our commitment must be to do so, we can together sustain and expand a powerfully significant conversation on patient experience improvement at all touch points of care in all systems and organizations providing care and respectful of all voices engaged in care from the providers, carers (as called in the UK) and support teams to the patients, residents, families and support networks that are impacted by what occurs in healthcare every day.

Gathering Places Will Remain Central to our Movement

If we return to the concept of community, whether local and physical as some or global and virtual as ours, they all require a gathering place. As professionals have found great support in coming together via our affiliate, The Beryl Institute, we too provide a space here with our virtual gathering place in PXJ. As we continue to engage more individuals, bringing together researchers and academics, connecting practitioner-scholars with organizational innovators, creating windows of voice and perspective from patients and families to maintain both context and awareness, we will continue to be a symphony of contributions and ideas on which we can all build. If we are true to our intention, we will work diligently to ensure broad voices are heard, rigorous exploration is encouraged, measureable practices highlighted and the impact of all this work in healthcare celebrated.

This concept of experience – be it for patients, residents, families or those providing care – is much too critical to leave to chance. If we are committed to coming together to learn, share and grow then we not only own a piece of this movement, but we share in the opportunity to lead it. These are the very ripples Mother Teresa encouraged each of us to create and I invite you to join us.

We are excited and honored to bring you Issue 2 of Patient Experience Journal and what I shared in launching our inaugural issue still holds true. What we do here together can only lead to good things for all seeking or delivering care. It is a cause for which we should (and will) remain relentless. Here is to continuing this great journey together.

Jason A. Wolf, PhD
Editor
November 20, 2014