Why the Rotationplasty Patient-Powered Registry Is Crucial for Shared Decision Making: "We need as much research as we can get!"

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Significance: Rotationplasty (RP) is a rare but increasingly requested option for knee tumors, yet its long-term outcomes remain poorly understood. The absence of a central data repository and a dedicated billing code limits research, contributing to clinical bias and underrepresentation of RP in shared decision-making.

Innovation: Patient-powered registries serve as a database of health information, managed by patient advocates in their own words with the purpose of understanding patient-specific needs and research priorities. The Rotationplasty Patient-Powered Registry was created to provide a longitudinal repository of patient-reported outcomes.

Approach: Parents of children and adults who have or had RP were invited to complete quantitative assessments including age-appropriate versions of the Patient-Reported Outcomes Measurement Information System (PROMIS), the Toronto Extremity Salvage Score (TESS-LE), MSTS Satisfaction Scale, and the Decision Regret Scale to measure limb function and quality of life. Patients were also asked to answer qualitative questions on appearance, function, prosthetics, and rehabilitation.

Results: To date, 12 participants with RP have completed the survey. Causes for RP include osteosarcoma (8), Ewing sarcoma (1), synovial sarcoma (1), congenital limb difference (1), and trauma (1). Two with osteosarcoma reported having a limb salvage surgery first, then later chose RP. Median age at surgery is 20.5 years (range 6-41 years); median time since surgery is 3.2 years (range 3 months to 40 years). Eight scored zero on the Decision Regret Scale; four scored low-mid regret. MSTS satisfaction results are shown in Table 1. Of adults with > 1 year follow-up, median T-scores were 52.5 for PROMIS-Global Physical Health (range 42.3-67.7), 56.2 for PROMIS-Mental Health (range 38.8-67.6), and 91.8 for TESS-LE (range 82.8-100).

Two analysts evaluated qualitative responses (Table 2), assisted by an institutionally approved AI version of Gemini.
Appearance. While initially described as "weird" or "jarring" without a prosthesis, patients generally report high levels of long-term satisfaction and comfort with their bodies. Themes include public perception, self-consciousness, and social interaction. Several noted being more self-conscious as young adults or shortly after surgery but grew more confident over time.
Function. Patients frequently choose rotationplasty to maintain a higher level of function than traditional amputation or limb salvage surgery (LSS) would allow. Themes include functionality (walking, hiking, weight-lifting, working long shifts), mobility aids, limitations, and comparison to limb salvage surgery (less pain, better stamina, improved range of motion).
Prosthetics. Finding a skilled, communicative prosthetist is described as essential for a successful outcome. Themes include provider experience, travel, socket comfort, and advancement with new technology.
Rehabilitation. Rehabilitation experiences varied from military-grade programs to self-guided recovery. Themes include brain rewiring for new limb orientation, gait training, alternative therapies (Pilates, lymphedema therapy), and barriers such as lack of local RP-specific services, insurance coverage limits, and past medical trauma from previous surgeries.

Discussion & Impact: The Rotationplasty Patient-Powered Registry provides a voice to a rare and understudied population. Understanding life after surgery can help clinicians and patients engage in shared decision-making and improve access to data for research. Research clinicians can apply for access to deidentified data after year one.

Table 1. Satisfaction Scale

Adult/Self: Please study each of the following statements carefully. Then select the one that most closely describes how you feel about rotationplasty. * must provide value

1) I am enthusiastic about it and would recommend it to others with the same problem.
2) I like it and would do it again.
3) I am satisfied and would do it again.
4) I accept it and would do it again.
5) I accept it but would not do it again if there was another choice.
6) I dislike it and would not do it again.

Parent: Please study each of the following statements carefully. Then select the one that most closely describes how you feel about rotationplasty for your child. * must provide value

1) I am enthusiastic about it and would recommend it to others with the same problem.
2) I like it for my child and would do it again.
3) I am satisfied for my child and would do it again.
4) I accept it for my child and would do it again.
5) I accept it for my child but would not do it again if there was another choice.
6) I dislike it for my child and would not do it again.

Time since RP	*Age at RP*	*Current age*	*Gender*	*Diagnosis*	*Satisfaction Scale Score*
3 months	**13**	**13**	**male**	**osteosarcoma**	**3 (parent)**
8 months	**31**	**32**	**male**	**synovial sarcoma**	**1 (self)**
1 year, 7 months	**41**	**43**	**female**	**osteosarcoma (age 13) failed limb salvage**	**1 (self)**
2 years, 2 months	**21**	**24**	**female**	**osteosarcoma**	**1 (self)**
2 years, 6 months	**6**	**9**	**female**	**osteosarcoma**	**1 (parent)**
3 years	**26**	**29**	**nonbinary**	**trauma**	**1 (self)**
3 years, 4 months	**35**	**38**	**female**	**osteosarcoma (age 32) failed limb salvage**	**1 (self)**
4 years	**16**	**21**	**female**	**osteosarcoma**	**1 (self)**
12 years	**20**	**32**	**female**	**PFFD**	**1 (self)**
12 years	**30**	**42**	**female**	**osteosarcoma**	**1 (self)**
40 years	**13**	**53**	**female**	**osteosarcoma**	**1 (self)**

Table 2. What I Want Surgeons to Know

Time since RP	*Age at RP*	*Current age*	*Gender*	*Diagnosis*	*Decision Regret Score 0 (none), 100 (high)*
3 months	**13**	**13**	**male**	**osteosarcoma**	**30**
Be kind and listen to your patient, this might be your everyday but it's not for families faced with this decision. empathy and bedside manner go a long way!!					
8 months	**31**	**32**	**male**	**synovial sarcoma**	**5**
A network should be built of rotationplasty patients who have recovered to be a resource to those new patients, considering a rotationplasty.					
1 year, 7 months	**41**	**43**	**female**	**osteosarcoma (age 13) failed limb salvage**	**0**
Neuroplasticity is not an issue at any age! ALL surgical interventions require a patient to relearn walking post-op and rotationplasty was not the most challenging of my walking rehabs.					
2 years, 2 months	**21**	**24**	**female**	**osteosarcoma**	**0**
I think it is so important to let patients know this is an option! The first surgeon I spoke with didn't tell me about this option. I almost went with an amputation at the hip because of it, and my quality of life would not have been great. I had someone reach out to my parents about the rotationplasty option and I found another surgeon who was able to perform the surgery for me. I'm so glad I had this option!					
2 years, 6 months	**6**	**9**	**female**	**osteosarcoma**	**0**
Having to make a surgical decision while you are in the midst of starting chemo is a very challenging time. We would like surgeons to know that it is important to provide patients with as many resources as possible to help make that decision.					
3 years	**26**	**29**	**nonbinary**	**trauma**	**5**
Phantom pain is not impossible with RP. Access to competent prosthetic care is real challenge. There appears to be limited at home resources for patient with RP. There needs to be more research in the outcomes of RP in adults. There needs to be more options to secure the socket and thigh corset to the residual limb.					
3 years, 4 months	**35**	**38**	**female**	**osteosarcoma (age 32) failed limb salvage**	**0**
Function is more important than looks! …I was 32 when I had my LSS, and I was told that I wouldn't be able to run, and would definitely need at minimum, another knee replacement should I live til my 60s. Every subsequent surgery I might have needed, no matter how skilled the surgeons are, increases the risk of infection. I don't think this is discussed as much as it probably should be.					
4 years	**16**	**21**	**female**	**osteosarcoma**	**0**
I want surgeons to know how important it is to prepare patients not only for the surgery itself, but also for life afterwards, both physically and mentally. For me, it made a big difference that my surgeons showed me videos and real examples of people living active, fulfilling lives with rotationplasty. It helped me understand that a good life is possible, even if it looks different. …I believe that combining clear information, visual examples, and proper rehabilitation guidance early on can greatly improve both recovery and long-term outcomes for future patients.					
12 years	**20**	**32**	**female**	**PFFD**	**10**
Discuss more of the post-op challenges/expectations. Give more photo examples and resources to patients. Would have been helpful to have a peer who had a rotationplasty to chat with prior to surgery. Give reassurance without dismissal. Shared decision making super important. Hand-outs if possible.					
12 years	**30**	**42**	**female**	**osteosarcoma**	**0**
…that I'm grateful for rotationplasty as an option as an adult. It should be offered to more adults. No phantom pain for most of us = that's well worth it even without the sportsy feats that some of the kids can do!					
40 years	**13**	**53**	**female**	**osteosarcoma**	**0**
Rotationplasty is no more difficult to deal with than the other surgical options. They are ALL difficult to face. In fact, it is my belief that RP is easier to deal with than amputation as I feel as though I still have my leg...albeit a little leg.					