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WRIST & HAND

A qualitative study of life satisfaction after surgery for adult traumatic brachial plexus injury

Aims

Brachial plexus injury (BPI) is an often devastating injury that affects patients physically and emotionally. The vast majority of the published literature is based on surgeon-graded assessment of motor outcomes, but the patient experience after BPI is not well understood. Our aim was to better understand overall life satisfaction after BPI, with the goal of identifying areas that can be addressed in future delivery of care.

Methods

We conducted semi-structured interviews with 15 BPI patients after initial nerve reconstruction. The interview guide was focused on the patient's experience after BPI, beginning with the injury itself and extending beyond surgical reconstruction. Inductive and deductive thematic analysis was used according to standard qualitative methodology to better understand overall life satisfaction after BPI, contributors to life satisfaction, and opportunities for improvement.

Results

Among the 15 patients interviewed, the following themes emerged: 1) happiness and life satisfaction were noted despite limitations in physical function; 2) quality of social support influences life satisfaction during recovery from BPI; and 3) social participation and having a sense of purpose impact life satisfaction during recovery from BPI.

Conclusion

How patients perceive their BPI treatment and recovery varies widely, and is not directly linked to their self-reported functional outcome. Patients with stronger social circles and activities that give them a sense of fulfillment were more likely to be satisfied with their current status. Evaluating a patient's social network, goals, and potential supportive adaptations early in the treatment timeline through coordinated multidisciplinary care may improve overall satisfaction during recovery from BPI.

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Introduction

Treatment of adult traumatic brachial plexus injury (BPI) remains challenging due to the limits of neural regeneration and the broad emotional and psychological impact of the injury. Many patients are not satisfied with their function after BPI and desire better treatment outcomes.¹⁻³ In the most severe cases, such as a complete BPI with root avulsion, the modest functional results after a "successful" surgical reconstruction leave patients wondering whether it was "worth it" to go through surgery and prolonged rehabilitation.^{1,3,4} Although there are few reports on return to employment after BPI, the existing literature suggests that a minority of patients return to the workforce in a meaningful way.⁵⁻⁹ These findings support the assertion by Franzblau et al¹ that the current strategies to manage BPI may be falling short of achieving satisfaction and meeting the functional expectations of patients. To address the shortcomings of our current approaches to BPI care, we conducted semistructured interviews with patients after BPI reconstruction. Our goal was to discuss life

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satisfaction after BPI, with the purpose of identifying areas that can be addressed during recovery from BPI.

Methods

After receiving approval from our institutional review board, we conducted semi-structured interviews with 15 patients who had undergone BPI reconstructive surgery. Based on inclusion criteria, the participants had surgery at least six months prior to interview recruitment and were all aged 18 years or older. In order to gather a representative cohort of patients and in accordance with established gualitative research approaches,¹⁰ we used purposive sampling strategies to recruit participants of both sexes, across various age ranges, at different stages of recovery (six to 12 months and > 12 months from surgery), and with varying levels of BPI injury severity (complete/pan-plexus BPI, supraclavicular partial BPI, and infraclavicular partial BPI). We recruited participants during routine clinical visits from our centre's multidisciplinary peripheral nerve injury clinic. At the conclusion of the clinical visit, the surgeon (CID) provided an overview of the study intent and protocol. Written informed consent was then obtained by research staff and interviews were conducted immediately following the clinic visit or scheduled for a future in-person interview. For those unable to participate immediately following their clinical visit or unable to come back for an in-person interview due to travel distance, phone interviews were used for seven participants to maximize participation.

Participants completed a brief demographic survey prior to the semi-structured interview. The interviews were conducted by a trained qualitative interviewer and a dedicated note-taker (LR). No personnel involved in the patient's clinical care were present during the interview. The interviews, which ranged from 45 minutes to over two hours, were audio-recorded and professionally transcribed.

A fellowship-trained, board certified hand surgeon (CID) with additional training in peripheral nerve and brachial plexus surgery developed the semi-structured interview guide. The interview guide was designed to allow participants to discuss the entirety of their experience after their initial injury, including the time preceding and following surgical reconstruction. The interview guide was reviewed by a researcher with extensive experience in qualitative research (ASI) and two other brachial plexus surgeons (WZR, DMB) at our centre's multidisciplinary peripheral nerve clinic. The interview guide was pilot-tested with three BPI patients, with adjustments made at the conclusion of each pilot interview. The interview guide included questions oriented towards changes in their physical limitations, emotional recovery, and social relationships. The interview guide covered multiple domains of recovery after

BPI, as previously reported by Mancuso et al:¹¹ pain, function, independence, limitations, appearance, finances, employment, and mood.

The interview transcripts were analyzed by three members of the research team (including a health psychologist and hand surgeon (CJD, LR, ASJ)) using inductive and deductive coding approaches, in accordance with established qualitative research methods.¹⁰ An initial codebook was developed by reviewing an initial series of interview transcripts. The team agreed upon revisions to the codebook after group discussion. All transcripts were uploaded into NVivo 12 (QSR International; Doncaster, Australia) to facilitate analysis. Each transcript was coded by two study team members (CID, LR) using the final codebook, with coding discrepancies resolved by discussion. Group discussion was used to ensure that data saturation had been reached (i.e. no new data were forthcoming from interview transcripts). Further discussion was used to organize the codes into themes. This manuscript focuses on themes and codes related to life satisfaction after BPI.

Results

The majority of participants were men (80%; 12/15; Table I). The median age was 48 years (range 27 to 69). Four patients were employed at the time of interview, two were unemployed, two were retired, six were on disability, and one patient did not mark an employment status. The median time from surgery to interview was 13 months (range 6 to 43) among the 15 participants interviewed (Table II). The injury severity ranged from complete/pan-plexus (n = 7), supraclavicular partial BPI (n = 4), and infractavicular partial BPI (n = 4). Surgical strategy typically included exploration of the brachial plexus, often with a combination of nerve grafts and nerve transfers (Table II). Two patients underwent freefunctioning muscle transfers as part of their primary reconstruction. Five patients had subsequent surgery (such as tendon transfers, contracture releases, tenolyses, or arthrodesis) to improve function.

Theme 1: happiness and life satisfaction were noted despite limitations in physical function. Out of 14 participants, 12 (86%) described feelings of overall happiness and life satisfaction during interviews, despite reporting limitations in their physical function (Table III). Many acknowledged their physical limitations, but described reaching a point where they were able to move beyond these limitations and adjust to a new state of normal after BPI. (*"I feel like I got to the point now where I don't feel like that at all. Like I - I don't feel disabled. I feel like I'm in pain, but I don't feel like I'm disabled. Which is just pretty awesome."* – Participant 3; 28-year-old male interviewed 13 months after surgical reconstruction for complete BPI). Getting to this point often required learning accommodations to accomplish the tasks of their daily lives, including developing and maintaining Table I. Demographic characteristics for interview participants.

Characteristic	Total (n = 15)
Age, yrs	
18 to 34	3
35 to 54	7
55+	5
Sex	
Female	3
Male	12
Race	
Black or African American	2
White	13
Marital status	
Married	7
Divorced	3
Separated	1
Living with partner	2
Never married	1
Widowed	1
Healthcare coverage	
Private health insurance	10
Medicaid	2
Medicare	2
Workers compensation	1
Education status	
Less than ninth grade	0
ninth to 11 th grade/12 th grade with no diploma	1
High school graduate	4
Some college, no degree	3
Associate's degree	3
Bachelor's degree	3
Master's degree	1
Employment status	
Full-time (including self-employed)	4
Part-time	0
Unemployed	2
Disabled	6
Homemaker	0
Student	0
Retired	2
Unknown	1
Annual household income (USD)	
0 to 14,999	1
15,000 to 29,999	2
30,000 to 44,999	2
45,000 to 49,999	1
50,000 to 59,999	2
60,000 to 84,999	5
85,000+	1
Unknown	1
Money available at the end of each month (for	
past 12 months)	
Not enough to make ends meet	6
Just enough to make ends meet	5
Some left over	4
Household food security at the end of each month (for past 12 months)	
Enough of the kinds of food we want or should eat	11

Continued

Table I. Continued

Characteristic	Total (n = 15)	
Enough, but not always the kind of food we want or should eat	2	
Sometimes not enough to eat	2	
Often not enough to eat	0	

optimism during the adjustment period. This was present among patients of all injury severities (panplexus, supraclavicular partial, and infraclavicular partial) ("The success is that I'm able to do what I need to do [...] A challenge sometimes, because my arm has physical limits that I can lift it for a period of time until it starts getting tired. So, there are still some challenges, but for the most part, I'm very happy with the recovery that I've made, and I feel like it's just going to get better with time." - Participant 1; 62-year-old male interviewed ten months after surgical reconstruction for upper trunk BPI). Participants noted the functional limitations that they had to accept, and used perspective on their personal progress as an adjustment tool. ("I can't close my hand all the way. I can just bend my fingers just a little bit. But at the same time, it's more than what I had, and I'm thankful for that. But still, it's, uh, it's tough to deal with." - Participant 5; 56-year-old male interviewed 39 months after surgical reconstruction for complete BPI).

Theme 2: quality of social support influences satisfaction during recovery from BPI. In describing the extent and quality of their social support network after BPI, many participants expressed a deep sense of gratitude and appreciation for the help provided by their family members and other caregivers (Table III). Most participants had insight into how their injury has affected the lives of the members of their support network. ("I know my life has changed [my wife's] life since the accident... I mean, it's aggravating to - to need someone like that." - Participant 2; 49-year-old male interviewed nine months after surgical reconstruction of complete BPI). Participants also conveyed a reluctance to rely on others, as many had been physically and emotionally independent prior to their injury. ("I still can't do it without [my wife and daughter], to be honest with you. It's because my wife still has to help me with bathing and dressing, things like that. That's why I'm hoping I can hurry and get more self-reliant and take a little bit more pressure off of them." - Participant 16; 69-year-old male interviewed nine months after surgical reconstruction of complete BPI).

In contrast to those who had strong support from family and friends, those participants without a robust support network noted the difficulty in adjusting to life after BPI. These participants expressed feelings of despair and frustration due to the lack of social support and conveyed a clear desire for greater support from family and friends. ("I wanted [my family] to be there

Sex	Age at interview, yrs	Injury severity	Surgery	Time from surgery to interview, mths
M	62	Upper trunk	Distal nerve transfer to restore elbow flexion	10
М	49	Complete BPI, partial recovery	Tendon transfers for restoration of radial nerve function	9
М	28	Complete BPI	Cable grafting from cervical roots to upper trunk and suprascapular nerve; spinal accessory to triceps nerve transfer; intercostal nerve transfers and free functioning muscle transfer to restore elbow flexion	13
F	68	Lower trunk	Exploration and neurolysis; subsequent tendon transfers for thumb opposition, dynamic anti-claw, and extrinsic finger flexion; thumb arthrodesis.	39
М	56	Complete BPI, partial recovery	Distal nerve transfers to restore elbow flexion and extrinsic finger extension	37
F	52	Medial cord, partial recovery	Distal nerve decompressions and neurolysis	9
М	47	Complete BPI, partial recovery	Distal nerve transfers for shoulder abduction and elbow flexion; distal nerve decompressions and neurolysis; subsequent finger contracture releases and tenolyses	39
М	47	Upper trunk, partial recovery (with neuropathic pain)	Neurolysis of brachial plexus	20
М	57	Posterior cord	Distal nerve transfer for shoulder abduction	16
М	43	Complete BPI	Cervical nerve grafts to upper trunk; distal nerve transfers for elbow flexion; spinal accessory to suprascapular nerve transfer	24
М	46	Posterior cord	Distal nerve transfer for shoulder abduction	6
М	51	Posterior cord	Posterior cord grafting and distal nerve transfer	6
F	27	Complete	Cervical nerve grafts to posterior cord; distal nerve transfer and intercostal nerve transfers for elbow flexion	43
М	69	Complete	Cervical nerve grafts for shoulder abduction; free functioning muscle transfer for elbow flexion	9
М	34	Upper trunk extended	Distal nerve transfers for shoulder abduction and elbow flexion; extraplexal nerve transfer with intercalary graft for elbow extension	8

Table II. Injury severity, surgical treatment, and time from surgery to interview.

BPI, brachial plexus injury; F, female; M, male.

with me to kind of be there for me, and it seemed like they kind of pushed me away. I was more of a bother and a nuisance, and they wanted to live their own lives." – Participant 10; 43-year-old male interviewed 24 months after surgical reconstruction of complete BPI).

Theme 3: social participation and having a sense of purpose impact satisfaction during recovery from BPI. Participants described the influence of social participation on satisfaction during their recovery (Table III). For four participants, this was described in the form of employment. Those participants who had been able to continue working described its positive impact on their recovery ("...my job probably definitely turned me around. Just gave me kind of purpose and I feel like when everybody has the accident you kind of lose that purpose. Because everything's different. It's just, "How do I—how do I still live life?" – Participant 3; 28-year-old male - interviewed 13 months after surgical reconstruction for complete BPI). Other participants who could not continue working conveyed its psychological and financial impact. ("[The disability application process was] Humiliating. Because I've always been one that has provided for my family, and I've always worked. And I'm-I've always been a hard worker, and having to go through this and file for disability and stuff has not been a lot of fun." – Participant 10; 43-year-old male interviewed 24 months after surgical reconstruction of complete BPI). For other participants, social participation was more associated with home and family life, describing a need to contribute domestically and to feel useful in some manner. Conversely, feelings of "uselessness" were reported ("Sometimes I feel un-useful, a little bit. We used to do little house projects all the time." – Participant 5; 56-year-old male interviewed 39 months after surgical reconstruction for complete BPI). One participant described using a fear of being useless as motivation for his recovery ("[Participant's mother] got a lot on her plate. And I felt really guilty because she was having to do everything. – Participant 15; 27-year-old female interviewed 43 months after surgical reconstruction for complete BPI).

Discussion

Qualitative analysis of interviews with 15 patients recovering from BPI demonstrates that the relationship between self-reported function and satisfaction is unclear. Many patients discussed overall satisfaction in life despite having relatively limited upper limb function. The concept of maintaining good or excellent quality of life despite substantial disability has been described as the "disability paradox".¹² The disability paradox has been demonstrated among

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Table III. Participant quotes organized by them	ne (in addition to those used in manuscript text).
Themes and participants	Quote
Adjustment to functional limitations	
Determination	
Paticipant 8, 47-year-old male, 20 mths after surgery for upper trunk BPI	"I lead a very functional life. I just learned how to do stuff differently, leverage-wise, and pick up things without using this arm as much It just took a while."
	"I can look at this couch and - and you can come over and say, "Is there any way you can help me load this couch in the back of my truck?" And, yeah, I can help you. My hand don't work the way it's supposed to, but, by God, we can get that couch loaded."
Participant 4, 68-year-old female, 39 mths after surgery for lower trunk BPI	"since I've done that [getting an adapted car], I feel like I can just probably do anything. It may take me a way of figuring out how to get it done, but I think I can just about do anything you put in front of me."
Participant 1, 62-year-old male, ten mths after surgery for upper trunk BPI	\cdot "So, I never looked at this injury as anything but a stepping stone to the next place I need to be."
Participant 3, 28-year-old male, 13 mths after surgery for complete BPI	"All I know was there's a lot of hopelessness in this injury. There's definitely lots of medical support and help that can be received. Overall I think it's a mental thing in how you are kind of perceiving everything."
Social support	
Appreciation and recognition of support network	
Participant 1	"It's been less of a challenge because of the family supportand the understanding of all my friends and relatives and co-workers."
Participant 10, 43-year-old male, 24 mths after surgery for complete BPI	"There's days when I feel like they're right beside me, and then there's days when I feel like they're not. It's been kind of a roller coaster ride, and it's been tough. I have thought that they [kind of] have distanced themselves from me, but this has been really hard on them, too."
Participant 6, 52-year-old male, nine mths after surgery for medial cord BPI	"I just think all the prayers and seeing everybody root you on, it's - it's a big thing. [] It's like, "Oh, I can do this. I don't want to let anybody down.""
Participant 3	"I'm definitely lucky to have the support system that I have, whether it be from work with them giving me extra time to come to things like this and the doctor and make work certain changes, and any kind of assistive device that I think I would need that that'll definitely work. Which I try not to, try to keep it on the regular stuff."
Reluctance to be dependent	
Participant 2, 49-year-old male, nine mths after	
surgery for complete BPI	"I mean, it's aggravating to – to need someone like that."
Participant 15, 27-year-old female, 43 mths after surgery for complete BPI	"my mom and dad always taught me to be independent instead of needing somebody, so, like, when I did need somebody, I'm like, "Ah. No. I can do it. I can do it." But no."
Participant 6	"Sometimes [my family members] coddle and it's like, you know, "Back up." And so—but I mean for the most part it's just they ask. You know, "What do you want me to do? What do you want me to not do?" And this is my immediate family, and most of them are really great about it. In the beginning, I was adamant about "Don't ask me if you can do something. I'll ask you if - if I need help.""
Participant 8	"you feel guilty because somebody is doing so much, and you aren't. And you're not pulling the load, uh, so to speak."
Participant 7, 47-year-old male, 39 mths after surgery for complete BPI	"There's nothing worse than feeling like you can't really do for yourself. That's the worst part about it."
Negative effects of poor support	
Participant 7	"My support system here is very small, and it - it gets real boring, and sometimes you feel like you're just, you know, you - you feeling like the walls are just closing in sometimes."
Participant 12, 46-year-old male, six mths after surgery for posterior cord BPI	"You better dig in, and you better have a good support network, or you better be strong enough to not need a support network, because, uh, you know, the hard part's going to be watching your body decay right before your eyes."

Social participation and sense of purpose **Employment/finances**

	"if my job didn't work for me and I had to figure something out [] I would probably be really messed
Participant 3	up."
Participant 12	"I will be that guy on the side of the road asking for money. There's nowhere—if you take away my ability to work, I - I have nothing to do. There's nothing that I could possibly do to come back from this."
Sense of purpose	
Participant 17, 34-year-old male, eight mths after surgery for upper trunk BPI	"I'm at that point where I'm—right, wrong, indifferent, I do need to make a decision as to what I'm going to do for the rest of my life."
Participant 16, 69-year-old male, nine mths after surgery for complete BPI	"So, you end up being sad about all this, which is understandable You don't need to do be that way, you know, especially since you got your wife and your daughter and your friends. You got this and this and this. You've got everything you had before."
Participant 15	"I do the things around the house and make sure everything's good and to be able to, like, contribute, I guess you would say."
Resignation	

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Continued

Table III. Continued

Themes and participants	Quote	
Participant 5, 56-year-old male, 37 mths after surgery for complete BPI	"I'd say a lot of it's my fault because I don't have the gumption or the initiative anymore to - to go out and try to do something. I'm happy with just sitting at home. And - and like I say, I'm 56 years old, so I think part of that is probably just my age. Not all of it, though. I think part of it's just, like, I don't want to mess with it. You know? Just—it—everything's different now and too hard."	
Participant 7	"You know, but there's nothing I do now that makes me feel accomplished or fulfilled. I feel more helpless— than anything just because I know that I'm not able to go out and have the use of both arms. And when you don't— you'll feel helpless you think about that, and that starts playing in the back of your mind What if you go out by yourself and you have to change a tire What if something happened to where, you know, I needed both hands?"	
Participant 9, 57-year-old male, 16 mths after surgery for posterior cord BPI	"But I've gotten to where I'm pretty well–I've accepted it, that it's never going to get any better, and I've accepted it and—and learned to live with it."	

BPI, brachial plexus injury

patients with spinal cord injury (SCI), with Hartoonian et al¹³ reporting that quality of life was not affected by the degree of functional impairment. However, the same authors demonstrated a relationship between quality of life and symptoms of major depressive disorder, such as anhedonia, depressed mood, feelings of failure, and suicidal ideation.¹³ Our analysis of interviews with BPI patients demonstrates similar findings, suggesting parallels between SCI and BPI. While this finding is intuitive and not necessarily surprising. it is important for members of the surgical and therapy teams to be aware of its applicability to BPI patients. This has particular importance when considering options for surgical reconstruction, as some of the psychological and personality characteristics of patients may be taken into account during the selection of specific procedures. For some patients, it may not be desirable and/or acceptable to spend 18 to 24 months awaiting outcomes from an extensive surgical procedure. Consideration should be given to factors outside of what is surgically "possible" and to what is better suited to the patient's individual desires,¹⁴ provided that the surgeons and therapists can offer appropriate counseling regarding realistic outcomes and timeframes. Furthermore, given the impact of emotional distress seen in our analysis and previously reported in BPI patients,¹⁵ multidisciplinary coordinated care with mental health specialists and psychological counseling can optimize quality of life after BPI, similar to SCI.^{16,17}

Prior investigation has shown that greater community participation and social integration are associated with lower somatic symptoms of depression and higher quality of life among SCI patients.¹³ In our qualitative analysis of interviews with BPI patients, among those reporting greater satisfaction we identified greater social support, and the ability to return to hobbies or work. Among SCI patients, emphasis has been placed on facilitating return to work, even if in a different capacity than before injury.¹⁸ Based on our findings, we believe that a similar emphasis on return to work or pre-injury interests should be used for BPI patients to optimize satisfaction and quality of life. We discuss the arduous recovery after BPI and emphasize adjustment to a "new reality".^{13,17} The lack of functional independence creates not

only logistical difficulties with activities of daily living, but can alter family dynamics and have stark household economic implications.^{10,18} Based on our analysis, we emphasize the importance of helping BPI patients identify a sense of purpose early during recovery, given its association with improved quality of life after other traumatic injuries, chronic disease, and in the general population.^{18–22} Acknowledging the meaningfulness of work and social participation to many individuals, we prioritize determination of when patients would be best suited for vocational rehabilitation, return to employment, additional education, and/or resuming or finding new hobbies. This determination is made with the expected functional recovery in mind, counseling patients appropriately regarding the current limitations of surgical reconstruction.

There are limitations of our study. Qualitative research methods are not designed to provide wholly generalizable findings. Rather, these methods are used to gain a deeper and contextual understanding of the participant's experience. However, our sampling strategy captured a broad variety of patients with regards to sex, age, and injury severity, suggesting that our findings may indeed be generalizable to other patients. We reached data saturation when interviewing this group of patients, indicating that additional interviews would not have yielded additional findings. Prior qualitative studies with BPI patients by Franzblau et al¹ and Mancuso et al³ included 12 and 23 patients, respectively, prior to reaching thematic saturation. Our sampling strategy also incorporated patients from earlier (six to 12 months) and later (> 12 months) in their post-surgery recovery. This was done as part of our purposive sampling strategy, so as to gather opinions representative of the patient experience after BPI.¹⁰ Follow-up studies could examine patients at different points of recovery with serial interviews or surveys. It should be noted that our median patient age (48 years) is greater than what is traditionally noted in BPI patients, which may affect generalizability to younger patients. Our findings may not be transferable to patients in other countries due to cultural differences, variations in injury epidemiology, and differences in treatment philosophies and local provision of social services. Because our intention was to focus on less frequently reported aspects of the patient experience after BPI, we did not include traditional measures of patient outcomes after BPI (such as manual muscle testing and joint range of motion). We also did not incorporate a patientreported quantitative measure of satisfaction, instead relying on accepted qualitative research methods to ascertain patient satisfaction. Based on our findings demonstrating the importance of emotional and psychological aspects of recovery, we agree with other BPI investigators that future clinical reports after BPI should include patient-reported outcome measures and assessments of quality of life and satisfaction.^{10,23} Future mixed-methods studies may benefit from inclusion of gual-

itative assessments with traditional measures of function. Lastly, we did not capture the experience of patient family members and caregivers. Interviews with these individuals would likely enrich the descriptions of the experience after BPI, but were beyond the scope of our research plan.²⁴ Future investigation into the interactions between BPI patients and their caregivers may lead to additional insights into how to improve delivery of care and the patient experience after BPI.

Our work supports the application of the disability paradox to BPI. This underscores the need to consider how we assess outcomes after BPI in practice and report them in the scientific literature. A prior systematic review has demonstrated that surgeon-reported muscle function is the primary, and sometimes only, manner used to report outcomes, with only 5% of BPI studies included a measure of quality of life.⁵ Given our finding that functional outcomes do not predictably align with satisfaction and quality of life among BPI patients, we encourage BPI clinicians and researchers to consider evaluation of outcomes using tools that encompass multiple domains of recovery, extending beyond isolated assessment of physical function. This coincides with the growing emphasis within health research on patient-reported outcomes and patient satisfaction.

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