

Validation of the Patient Generated Index for People with Severe Mental Illness

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Abstract

Objective: The Patient Generated Index (PGI) is a personalized quality of life (QOL) measure. This secondary analysis examined its psychometric properties with people with severe mental illness.

Methods: Three hundred and eleven people with severe mental illness participated in structured interviews at baseline, nine months, and 18 months.

Results: The PGI captured a range of self-defined life areas. PGI scores were correlated with measures of QOL, hope, and functioning, indicating concurrent (criterion) validity. The correlation with QOL, with the finding that PGI scores were significantly higher for people who were employed ($n = 42$) versus unemployed ($n = 269$) and for people without substance use disorder ($n = 269$) versus those with substance use disorder ($n = 42$), is indicative of construct validity.

Conclusions and Implications for Practice: The results support the suitability of the PGI as an idiographic measure for monitoring personalized QOL of people with severe mental illness.

Impact and Implications

This study provides validation of the use of the PGI as an idiographic, personalized measure of QOL with people with severe mental illness. The individualized nature of the measure makes it pertinent for use in the delivery of recovery-oriented services, providing a way to assess and monitor life domain areas that are specific and important to each person.

Keywords: Patient Generated Index, quality of life, idiographic, mental illness, community mental health

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Quality of life (QOL) is generally assessed using standardized measures of pre-determined life domains, which assume that all domains are relevant and equal in importance for everyone (Martin et al., 2007; Schalock et al., 2016). Practitioners are beginning to incorporate idiographic, or self-defined, measures into health assessments, measuring change based on personal definitions of QOL (Papou et al., 2017; Scott & Lewis, 2015). Such personalized measures are important in order to align with personalized care, promote person-centered care, and track individual recovery throughout treatment (Fisher, 2015; Kuspinar et al., 2019; Papou et al., 2017; Salyers & Zisman-Ilani, 2020; Weisz et al., 2011).

The Patient Generated Index (PGI) is based on life areas that individuals define and weight by importance, thereby measuring QOL differently than standardized measures (Haynes et al., 2009; Mayo et al., 2017; Ruta et al., 1994). Developed in English, it has been validated across a wide range of physical health conditions, such as cancers and brain injuries (Aburub & Mayo, 2017; Hogan et al., 2013; Martin et al., 2007). However, it has not yet been validated with people with mental illness. This study contributes validation findings on an idiographic QOL measure that assesses and monitors the personalized treatment needs and priorities of people with severe mental illness.

Methods

Participants

This paper presents the findings of a secondary analysis of a longitudinal study of 311 people with severe mental illness, examining the relationship between fidelity to strength-based case management and client outcomes. Participants were recruited from seven community mental health agencies in three Canadian provinces. They were new recipients of the

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intervention, which focuses on fostering people's strengths to meet their personal goals (Rapp & Goscha, 2012).

Measures

PGI. For this study, the PGI was adapted for people with severe mental illness. Participants completed it as part of in-person interviews conducted in English or French based on their preference. The English version was translated into French (see online supplement) by a bilingual researcher and reviewed by another team member with mastery of both languages. In order to complete the PGI, people identify five life areas most affected by their mental illness. They then rate each area on a scale from 0 to 100, with 0 being "the worst you could imagine" and 100 being "exactly as you would like it to be." They rate a sixth item representing all other life areas. Finally, people allocate 60 points across the six life areas to weight where they most want improvement. The total score is calculated by multiplying each of the six ratings (0-100) in the second step by the proportions allocated in the final stage and summing this product.

In this study, we used the "blind" PGI - people were not shown their previous items at subsequent follow-ups (Martin et al., 2007). In the few instances where people had difficulty identifying life areas, they were prompted with a list of commonly mentioned life areas.

Other measures. Three standardized questionnaires were administered with the PGI: Lehman's 20-item Quality of Life Interview (QOLI-20 [Lehamn, 1988]), the Multnomah Community Ability Scale (MCAS [Barker et al., 1994]), and the Trait Hope Scale (THS [Snyder et al., 1991]).

Client administrative data were used to assign people to groups hypothesized to have dissimilar QOL (known-groups method [Portney & Watkins, 2009]), namely,

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employed/unemployed, stable/non-stable housing, and presence/absence of a diagnosis (bipolar disorder, substance use disorder, schizophrenia, and borderline personality disorder).

Procedure and Analysis

People participated in structured interviews at baseline, nine months, and 18 months, during which the PGI and additional measures were administered in order to measure client outcomes over the course of receiving strength-based case management. A power analysis (G*Power) indicated a power estimation of .95 for finding a significant correlation of $r(309) = .20$ at $p < .05$ with our sample ($n = 311$). Using the smallest subgroup sample ($n = 42$) in the known-groups analysis, an effect size of .40 indicated a power estimation of .67 for finding significant differences at the $p < .05$ level.

Due to the variability in life areas between PGI respondents, factor analysis was not suitable (Haynes et al., 2009). Instead, a researcher coded PGI life areas, inductively, and two other researchers validated the coding. The frequencies of the resulting domains, and their prioritized weightings, provided insight into commonalities and variations of responses.

We analyzed the correlation of PGI scores across time, and used the QOLI-20, THS, and MCAS to measure concurrent (criterion) validity. The QOLI-20 was also used to examine construct validity, given that it also measures subjective QOL, though in a standardized way. Known-groups analyses provided an additional measure of construct validity.

Results

Most participants (78%) completed the PGI at all time points, comparable to the QOLI-20 completion rate of 80% across time. PGI total scores increased between each time point. The mean total score (out of 100) was 30.18 ($SD = 21.03$, $n = 294$) at baseline, 31.58 ($SD = 21.65$, $n = 250$) at nine months, and 33.22 ($SD = 22.86$, $n = 242$) at 18 months. By the end of the study

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period at 18 months, PGI scores were significantly higher than baseline scores ($t(310) = 2.76, p < .01$) with a small effect size of $g_{Hedges} = 0.16$ (Table 1).

PGI Coded Domains

Table 2 provides a summary of the frequencies and weightings of the seven coded PGI domains. The approximately 1,000 distinctly-worded life areas identified at each time point (3,020 overall) mostly fell into one of four domains: relationships/socializing (30% at baseline), personal care (20% at baseline), vocational activities (15% at baseline), and daily living activities (14% at baseline). The remaining domains each represented less than 10% of life areas, and included personal growth, leisure activities, and going out. An “other” category included areas that did not fit into a domain. Frequencies of domains remained consistent across time. Average weightings were small and differences across time were small.

Correlation of PGI Scores Across Time

PGI scores were correlated across all time points. Baseline scores were significantly correlated with 9-month scores ($r[309] = .28$) and 18-month scores ($r[309] = .28$). Nine-month scores were significantly correlated with 18-month scores ($r[309] = .22$ [all p values $< .01$]).

Correlations with Other Measures (Concurrent and Construct Validity)

The PGI was significantly correlated with the QOLI-20, THS, and MCAS across all time points. The PGI correlations with the QOLI-20 were $r(309) = .34$ at baseline, $r(309) = .32$ at nine months, and $r(309) = .29$ at 18 months. The PGI correlations with the THS were $r(309) = .30$ at baseline, $r(309) = .19$ at nine months, and $r(309) = .17$ at 18 months. The PGI correlations with the MCAS were $r(309) = .26$ at baseline, $r(309) = .29$ at nine months, and $r(309) = .22$ at 18 months (all p values $< .01$).

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Group Differences (Construct Validity)

Regarding groups hypothesized to have different PGI scores, baseline scores for people who were employed ($M = 36.98$, $SD = 21.64$) were higher than those for the unemployed group ($M = 29.74$, $SD = 29.74$). This difference was significant ($t(309) = -2.1$, $p < .05$), with a small-to-medium effect size of $g_{Hedges} = 0.35$. At 18 months, PGI scores for people with substance use disorder ($M = 28.12$, $SD = 21.96$) were lower than for those without substance use disorder ($M = 35.65$, $SD = 20.45$). This difference was significant ($t(309) = 2.2$, $p < .05$), with a small-to-medium effect size of $g_{Hedges} = 0.36$. There were no other significant subgroup differences in PGI scores.

Discussion

In this study, the PGI captured a wide range of people's self-defined life areas affected by their mental illness. PGI scores remained consistent across time, with a small but significant correlation around $r(309) = .30$, likely due to the gap of nine months between scores, its individualized nature across time, and intervention effects (Papou et al., 2017). The PGI exhibited concurrent and construct validity. These findings were consistent with those of previous PGI studies with people with physical health problems (Camilleri-Brennan et al., 2002; Ruta et al., 1994; Tavernier et al., 2011).

In order to address this study's limitations, further research with a larger French sample is needed to compare the psychometric properties of the PGI in the two languages. In addition, the known-groups method was under-powered; hence, a larger sample is needed to examine group differences more closely. Finally, correlations of PGI scores across smaller time spacings (e.g., two weeks) is needed to determine test-retest reliability.

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Overall, the study results on the psychometric properties of the PGI begin to support the suitability of its use with people with severe mental illness. As an idiographic measure, it assesses QOL much differently than measures with pre-determined, standardized domains, giving more voice to people, and aligning with a recovery orientation. As such, the PGI provides a personalized way to assess the choices, needs and priorities of people with severe mental illness. It has the potential to be a useful monitoring tool for tracking the outcomes of people with severe mental illness over the course of receiving person-centered services.

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References

- Aburub, A. S., & Mayo, N. E. (2017). A review of the application, feasibility, and the psychometric properties of the individualized measures in cancer. *Quality of Life Research, 26*, 1091-1104. <https://doi.org/10.1007/s11136-016-1458-4>
- Barker, S., Barron, N., McFarland, B. H., & Bigelow, D. A. (1994). A community ability scale for chronically mentally ill consumers: Part I. Reliability and Validity. *Community Mental Health Journal, 30*, 363-383. <https://doi.org/10.1007/BF02207489>
- Camilleri-Brennan, J., Ruta, D. A., & Steele, R. J. C. (2002). Patient generated index: New instrument for measuring quality of life in patients with rectal cancer. *World Journal of Surgery, 26*, 1354-1359. <https://doi.org/10.1007/s00268-002-6360-2>
- Fisher, A. J. (2015). Toward a dynamic model of psychological assessment: Implications for personalized care. *Journal of Consulting and Clinical Psychology, 83*(4), 825-836. <https://doi.org/10.1037/ccp0000026>
- Haynes, S. N., Mumma, G. H., & Pinson, C. (2009). Idiographic assessment : Conceptual and psychometric foundations of individualized behavioral assessment. *Clinical Psychology Review, 29*, 179-191. <https://doi.org/10.1016/j.cpr.2008.12.003>
- Hogan, M., Nangle, N., Morrison, T. G., & McGuire, B. E. (2013). Evaluation of the patient generated index as a measure of quality-of-life in people with severe traumatic brain injury. *Brain Injury, 27*, 273-280. <https://doi.org/10.3109/02699052.2012.743177>
- Kuspinar, A., Mate, K., Lafontaine, A., & Mayo, N. (2019). Evaluating the content validity of generic preference-based measures for use in Parkinson's disease. *Parkinsonism and Related Disorders, 62*, 112-116. <https://doi.org/10.1016/j.parkreldis.2019.01.014>

THE PATIENT GENERATED INDEX AND MENTAL ILLNESS

- Lehman, A. F. (1988). A quality of life interview for the chronically mentally ill. *Evaluation and Program Planning, 11*(1), 51-62. [https://doi.org/10.1016/0149-7189\(88\)90033-X](https://doi.org/10.1016/0149-7189(88)90033-X)
- Martin, F., Camfield, L., Rodham, K., Kliemty, P., & Ruta, D. (2007). Twelve years' experience with the patient generated index (PGI) of quality of life: A graded structured review. *Quality of Life Research, 16*(4), 705-715. <https://doi.org/10.1007/s11136-006-9152-6>
- Mayo, N. E., Aburub, A., Brouillette, M., Kuspinar, A., Moriello, C., Rodriguez, A., & Scott, S. (2017). In support of an individualized approach to assessing quality of life: Comparison between patient generated index and standardized measures across four health conditions. *Quality of Life Research, 26*, 601-609. <https://doi.org/10.1007/s11136-016-1480-6>
- Papou, A., Hussain, S., McWilliams, D., Zhang, W., & Doherty, M. (2017). Responsiveness of SF-36 Health Survey and patient generated index in people with chronic knee pain commenced on oral analgesia: Analysis of data from a randomised controlled clinical trial. *Quality of Life Research, 26*(3), 761-766. <https://doi.org/10.1007/s11136-016-1484-2>
- Portney, L. G., & Watkins, M. P. (2009). *Foundations of Clinical Research: Applications to Practice* (3rd ed.). Pearson Education.
- Rapp, C. A., & Goscha, R. J. (2012). *The Strengths Model, 3rd Ed.* New York: Oxford University Press. ISBN: 978-0-19-976408-2
- Ruta, D. A., Garratt, A. M., Leng, M., Russell, I. T., & MacDonald, L. M. (1994). A new approach to the measurement of quality of life: The patient generated index. *Medical Care, 32*(11), 1109-1126. <https://doi.org/10.1097/00005650-199411000-00004>

THE PATIENT GENERATED INDEX AND MENTAL ILLNESS

Salyers, M.P., & Zisman-Ilani, Y. (2020). Shared decision-making and self-directed care. In:

H.H. Goldman, R. Frank, & J. Morrissey (Eds.), *The Palgrave handbook of American mental health policy* (pp. 197-2280. Palgrave MacMillan. https://doi.org/10.1007/978-3-030-11908-9_8

Scott, K., & Lewis, C. C. (2015). Using measurement-based care to enhance any treatment.

Cognitive and Behavioral Practice, 22(1), 49-59.

<https://doi.org/10.1016/j.cbpra.2014.01.010>

Schalock, R. L., Verdugo, M. A., Gomez, L. E., & Reinders, H. S. (2016). Moving us toward a

theory of individual quality of life. *American Journal on Intellectual and Developmental Disabilities*, 121, 1-12. doi: 10.1352/1944-7558-121.1.1

Snyder, C. R., Harris, C., Anderson, J. R., Holleran, S. A., Irving, L. M., Sigmon, S. T.,

Yoshinbou, L... & Harney, P. (1991). The will and the ways: Development and validation of an individual-differences measure of hope. *Journal of Personality and Social Psychology*, 60, 570-585.

Tavernier, S., Totten, A. M., & Beck, S. L. (2011). Assessing content validity of the patient

generated index using cognitive interviews. *Qualitative Health Research*, 21, 1729-1738. doi: 10.1177/1049732311420169

Weisz, J. R., Chorpita, B. F., Frye, A., Ng, M. Y., Lau, N., Bearman, S. K., Ugueto, A. M.,

Langer, D. A., & Hoagwood, K. E. (2011). Youth top problems: Using idiographic consumer-guided assessment to identify treatment needs and to track change during psychotherapy. *Journal of Consulting and Clinical Psychology*, 79(3), 369-380.

<https://doi.org/10.1037/a0023307>

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Table 1

Demographic Characteristics of Study Participants

		Participants (N = 311)	
		n (%)	<i>M (SD)</i>
Age (years)			40.32 (13.1)
Client Sex			
	Female	155 (51%)	
	Male	149 (48%)	
	Transsexual or transgender	2 (1%)	
Language (PGI version)			
	French	101 (33%)	
	English	210 (67%)	
Primary Diagnostic Category			
	Schizophrenia/Schizoaffective Disorder	86 (28%)	
	Borderline Personality Disorder	62 (20%)	
	Bipolar Disorder	54 (17%)	
	Comorbid with Substance Use Disorder	42 (14%)	
	Unemployed at Baseline	269 (87%)	
	Unstable housing (e.g. on the streets, emergency shelter, couch surfing)	58 (19%)	

Note. *M* = Mean, *SD* = standard deviation

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Table 2

Frequencies and Average Weightings of Life Domains at Baseline, 9 Months, and 18 Months

Domains	Baseline		9 Months		18 Months	
	<i>n</i> (%)	<i>M</i> (<i>SD</i>)	<i>n</i> (%)	<i>M</i> (<i>SD</i>)	<i>n</i> (%)	<i>M</i> (<i>SD</i>)
Relationships / socializing ^a	347 (30%)	7.6 (9.9)	255 (27%)	6.8 (8.2)	252 (28%)	8.8 (10.3)
Personal care ^b	234 (20%)	6.7 (8.3)	230 (24%)	7.5 (10.2)	202 (22%)	7.1 (8.2)
Vocational activities ^c	174 (15%)	7.4 (9.9)	126 (13%)	6.9 (10.7)	121 (13%)	10.5 (12.0)
Daily living activities ^d	163 (14%)	7.1 (9.8)	130 (14%)	6.5 (6.6)	109 (12%)	6.4 (7.7)
Personal growth ^e	104 (9%)	6.0 (7.4)	81 (9%)	7.8 (10.2)	78 (9%)	7.0 (12.6)
Leisure activities ^f	74 (6%)	4.8 (6.6)	59 (6%)	5.5 (7.1)	65 (7%)	6.4 (9.7)
Going out ^g	58 (5%)	6.2 (15.6)	59 (6%)	5.5 (7.0)	69 (8%)	5.4 (9.5)
Other ^h	8 (1%)		9 (1%)		13 (1%)	
Total	1,162		949		909	

Note. *n* = number, *M* (*SD*) = average PGI weightings and standard deviations

^a Examples of participants' wording of life areas within this domain: talk to daughter; relationship with boyfriend; social life.

^b Examples: sleep; hygiene; taking care of self.

^c Examples: working; going back to school; volunteer work.

^d Examples: household chores; laundry; grocery shopping.

^e Examples: self-esteem; control of addictive behaviour; ability to say no.

^f Examples: hobbies; writing poetry; play on my tablet.

^g Examples: going out; I can't go far from home; taking the bus.

^h Examples: having a computer; crossing a bridge; being told what to do.