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Validation of the Questionnaire for Impulsive-Compulsive Disorders in Parkinson's Disease (QUIP)

Daniel Weintraub, MD^{1,2,3,4}, Staci Stewart, BA¹, Judy A. Shea, PhD^{5,6}, Kelly E. Lyons, PhD⁷, Rajesh Pahwa, MD⁷, Erika D. Driver-Dunckley, MD⁸, Charles H. Adler, MD, PhD⁸, Marc N. Potenza, MD, PhD⁹, Janis Miyasaki, MD, MEd, FRCPC¹⁰, Andrew D. Siderowf, MD, MSCE², John E. Duda, MD^{2,3}, Howard I. Hurtig, M.D.², Amy Colcher, MD², Stacy S. Horn, DO², Matthew B. Stern, MD^{2,3}, and Valerie Voon, MD¹¹

¹ Department of Psychiatry, University of Pennsylvania, Philadelphia, PA

² Department of Neurology, University of Pennsylvania, Philadelphia, PA

³ Parkinson's Disease Research, Education and Clinical Center (PADRECC), Philadelphia Veterans Affairs Medical Center, Philadelphia, PA

⁴ Mental Illness Research, Education and Clinical Center (MIRECC), Philadelphia Veterans Affairs Medical Center, Philadelphia, PA

Corresponding Author: Daniel Weintraub, MD, 3615 Chestnut St., Room 330, Philadelphia, PA 19104-2676, phone: (215) 349-8207, fax: (215) 349-8389, weintrau@mail.med.upenn.edu.

Supplementary material: Four versions of the QUIP (full and short versions that assess for ICDs currently or anytime during PD) and scoring instructions are available online as supplementary material.

Authors' Contributions:

Daniel Weintraub, MD: study conception and execution; statistical analysis design, execution, and review and critique; and manuscript first draft preparation, review and critique

Staci Stewart, BA: study conception and execution; statistical analysis execution; and manuscript first draft preparation, review and critique

Judy A. Shea, PhD: study conception; statistical analysis design, review and critique; manuscript review and critique

Kelly E. Lyons, PhD: study execution and manuscript review and critique

Rajesh Pahwa, MD: study execution and manuscript review and critique

Erika D. Driver-Dunckley, MD: study execution and manuscript review and critique

Charles H. Adler, MD, PhD: study execution and manuscript review and critique

Marc N. Potenza, MD, PhD: study conception; statistical analysis review and critique; and manuscript review and critique

Janis Miyasaki, MD: study conception and manuscript review and critique

Andrew D. Siderowf, MD: study conception and execution; manuscript review and critique

John E. Duda, MD: study conception and execution; manuscript review and critique

Howard I. Hurtig, MD: study conception and execution; manuscript review and critique

Amy Colcher, MD: study execution and manuscript review and critique

Stacy S. Horn, DO: study execution and manuscript review and critique

Matthew B. Stern, MD: study conception and execution; statistical analysis review and critique; and manuscript review and critique

Valerie Voon, MD: study conception and manuscript review and critique

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⁵ Department of Medicine, University of Pennsylvania, Philadelphia, PA

⁶ Center for Health Equity Research and Promotion (CHERP), Philadelphia Veterans Affairs Medical, Philadelphia, PA

⁷ Department of Neurology, University of Kansas Medical Center, Kansas City, KS

⁸ Department of Neurology, Mayo Clinic Scottsdale, Scottsdale, AZ

⁹ Department of Psychiatry, Yale University, New Haven, CT

¹⁰ Division of Neurology, University of Toronto, Toronto, Canada

¹¹ National Institute of Neurological Disorders and Stroke (NINDS), Bethesda, MD

Abstract

Objective—As no comprehensive assessment instrument for impulse control disorders (ICDs) in Parkinson’s disease (PD) exists, the aim of this study was to design and assess the psychometric properties of a self-administered screening questionnaire for ICDs and other compulsive behaviors in PD.

Methods—The Questionnaire for Impulsive-Compulsive Disorders in Parkinson’s Disease (QUIP) has 3 sections: Section 1 assesses four ICDs (involving gambling, sexual, buying, and eating behaviors), Section 2 other compulsive behaviors (punding, hobbyism and walkabout), and Section 3 compulsive medication use. For validation, a convenience sample of 157 PD patients at 4 movement disorders centers first completed the QUIP, and then was administered a diagnostic interview by a trained rater blinded to the QUIP results. A shortened instrument (QUIP-S) was then explored.

Results—The discriminant validity of the QUIP was high for each disorder or behavior (receiver operating characteristic area under the curve [ROC AUC]: gambling=0.95, sexual behavior=0.97, buying=0.87, eating=0.88, punding=0.78, hobbyism=0.93, walkabout=0.79). On post hoc analysis, the QUIP-S ICD section had similar properties (ROC AUC: gambling=0.95, sexual behavior=0.96, buying=0.87, eating=0.88). When disorders/behaviors were combined, the sensitivity of the QUIP and QUIP-S to detect an individual with any disorder was 96% and 94%, respectively.

Conclusions—Scores on the QUIP appear to be valid as a self-assessment screening instrument for a range of ICDs and other compulsive behaviors that occur in PD, and a shortened version may perform as well as the full version. A positive screen should be followed by a comprehensive, clinical interview to determine the range and severity of symptoms, as well as need for clinical management.

Keywords

Parkinson’s disease; impulse control disorders; dopamine dysregulation syndrome; punding; pathological gambling

INTRODUCTION

Impulse control disorders (ICDs) are a group of psychiatric disorders whose essential feature is the failure to resist an impulse, drive, or temptation to perform an act harmful to either the self or others (1). ICDs that have been reported to occur in Parkinson’s disease (PD) include compulsive gambling, buying, sexual, and eating behaviors(2).

Case reporting(3) and cross-sectional studies(4–6) suggest that prevalence estimates for ICDs may be higher in Parkinson’s disease (PD) as compared with the general population(7–13) or with healthy control subjects(14;15), and it is not unusual for a patient to have multiple ICDs (16). Preliminary prevalence (either current or anytime during PD) estimates for ICDs in PD patients overall are 1.7–6.0% for problem or pathological gambling, 2.0–10.0% for compulsive

sexual behavior, and 0.4–1.5% for compulsive buying(2;17;18); there are no formal prevalence estimates for compulsive or binge-eating in PD. There is strong evidence of an association between dopamine agonist (DA) use and a range of ICDs and other compulsive behaviors in PD(2;4;6).

Other compulsive behaviors reported in PD include: (1) dopamine dysregulation syndrome (DDS) or hedonic homeostatic dysregulation, an addiction-like state marked by compulsive dopaminergic medication usage, particularly levodopa and short-acting dopamine agonists (e.g., subcutaneous apomorphine)(19); (2) punding, an intense fascination with meaningless movements or activities (e.g., cleaning, examining objects, or arranging) reported in 1.4–13.8% of PD patients(20;21); (3) hobbyism, a complex form of punding characterized by intense fascination with a specific activity or hobby (e.g. writing, repairing or dismantling things, working on projects, or computer use)(2); and (4) walkabout, defined as excessive, aimless wandering (walking or driving)(19).

As patients may not report such behaviors to their treating neurologist either due to embarrassment or because they do not suspect an association with PD pharmacotherapy, ICD behaviors appear to be under-recognized in clinical practice(4), potentially prolonging the psychosocial consequences associated with these disorders. Thus, an instrument to screen for the range of ICDs and other compulsive behaviors is necessary to ensure their detection. However, no such instrument has been developed and validated for use in PD. The Questionnaire for Impulsive-Compulsive Disorders in Parkinson's Disease (QUIP) was designed with the goal of having a brief, self-completed screening instrument for use in clinical care and clinical research that covers the range of impulsive-compulsive behaviors reported in PD.

METHODS

Questionnaire development

First, existing screening and diagnostic instruments for ICDs and other compulsive behaviors that have been used in PD and the general population were reviewed(1;6;19;21–23). Second, input was solicited from outside experts in the area of ICDs in PD (MNP, JM, and VV) and from an expert in questionnaire development (JAS). Third, a preliminary ICD section of the QUIP was structured to be consistent with diagnostic criteria or defining clinical characteristics as described in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR)(1). This consisted of an introductory question and four additional questions that addressed cognitive symptoms, affective symptoms, lack of ability to reduce or stop the behaviors, and activities that enable continuation of the behaviors. The compulsive medication use section was modeled on both Giovannoni's proposed criteria for hedonistic homeostatic dysregulation and DSM-IV substance dependence criteria. While minor wording changes were made in subsequent drafts, the structure of these sections remained consistent throughout the instrument development process. The other compulsive behaviors section was designed with conciseness in mind (an introductory question for each of the three behaviors plus two common additional questions). Guiding principles in the design of the QUIP included making it self-administered, brief yet comprehensive, and consistent in wording across different ICDs and other compulsive behaviors.

Next, the preliminary QUIP was administered to a sample of healthy controls (10 research staff members who work with neurodegenerative disease and psychiatric populations), and modifications were made based on the feedback received. Finally, the QUIP was administered to five PD patients and their informed others, and additional modifications were made based on the feedback received from them.

The final version that was validated queried about behaviors that occurred at any time since the onset of PD (either inactive or active) that lasted at least four weeks. We chose the time frame of “anytime during PD” due to the observation that a substantial number of PD patients who have experienced an ICD during PD are currently asymptomatic due to clinical management, but may be at elevated risk of developing an ICD in the future. Another version of the QUIP that queries only about active behaviors is also available; it is identical to the validated version except for the time frame queried. The final version of the QUIP is divided into three sections: (1) five questions (including an introductory question that defines and gives examples of problem behaviors) for the four ICDs reported in PD; (2) three distinct introductory questions and two common additional questions for hobbyism, punting, and walkabout; and (3) five questions (including an introductory question) for compulsive medication use. The Flesch-Kincaid Readability Test assessed the QUIP to require a 12th grade reading level.

Subjects for validation process

A convenience sample of 157 patients with idiopathic PD was assessed at four movement disorders centers between December 2007 and April 2008 (see Table 1 for demographic and clinical characteristics). The diagnosis of PD was confirmed by the patient’s movement disorder neurologist. Patients were identified either in the context of routine clinical care or on the basis of having an ICD sometime during PD; the latter was done to enrich the sample with ICD patients. The Institutional Review Board at each participating institution approved the study, and written informed consent was obtained from subjects prior to study participation.

Validation process

The QUIP instructs patients to answer questions based on behaviors lasting at least four weeks occurring anytime after PD onset. After completing the QUIP, the patient was administered a “gold standard”, semi-structured, diagnostic interview for compulsive gambling(1), buying (23), sexual behavior(6), eating(1), DDS(19), punting(19), hobbyism(2), and walkabout(19). Compulsive gambling included those patients with either problem or pathological gambling based on recommended cut-off points(24). The DSM-IV-TR research criteria for binge-eating disorder were modified to include general overeating in addition to discrete binge-eating episodes. The original criteria for walkabout were modified to exclude akathisia in order to capture purposeless wandering rather than a physical sensation of restlessness.

Prior to study initiation, each site identified research staff to administer the diagnostic interview who would be blinded to the results of the ICD questionnaire and unaware of the patient’s ICD history. In addition, all raters administering the diagnostic interview received in-person or telephone training from the primary investigator (DW) on how to apply the diagnostic criteria for each disorder or behavior.

Analyses

A receiver operating characteristic (ROC) curve was plotted for each of the disorders/ behaviors. The area under curve (AUC), sensitivity, specificity, positive predictive value (PPV), and negative predictive value (NPV) were calculated for each disorder/behavior. The optimal cutoff score for each disorder/behavior was the point of maximum combined sensitivity and specificity; in order for a screening instrument to effectively differentiate individuals with and without an ICD, it should have high sensitivity and specificity (i.e., discriminant validity), as this maximizes the proportion of patients whose test results are accurate. Post hoc analyses were conducted to determine if a shortened version of the QUIP (QUIP-S) had similar psychometric properties to the full questionnaire.

RESULTS

ICD frequencies

Frequencies of the different disorders and behaviors sometime during PD based on the diagnostic interview were: problem or pathological gambling (7.0%), compulsive sexual behavior (8.9%), compulsive buying (6.4%), compulsive eating (4.5%), punning (10.2%), hobbyism (14.6%), walkabout (3.2%), and compulsive medication use (<1.0%).

Overall, 31.2% of patients had a history of one or more ICDs, other compulsive behaviors, or compulsive medication use sometime during the course of PD. Approximately half of those subjects (15.9% of entire sample) had a history of a single disorder or behavior, and the other half (15.3%) had a history of two or more disorders or behaviors. Punning and hobbyism were usually distinct behaviors, with 18.5% of the population having only punning (7.0%) or hobbyism (11.5%), and 3.2% of the population having both punning and hobbyism.

The median completion time for the QUIP was 5 minutes.

QUIP

ICD section—The optimal cutoff point (i.e., point of maximum combined sensitivity and specificity) for each ICD was: (1) gambling: affirmative answers to ≥ 2 questions; (2) sexual behavior: ≥ 1 questions; (3) buying: ≥ 1 questions; and (4) eating: ≥ 2 questions (Table 2). These cut-off points provided at least 80% sensitivity and specificity for each ICD.

Other compulsive behaviors sections—For other compulsive behaviors, each introductory question by itself provided optimal sensitivity and specificity (Table 3). The discriminant validity of the single question for hobbyism was similar to that for the ICD section (sensitivity=0.96, specificity=0.90), while the questions for punning and walkabout had similarly high specificity but lower sensitivity.

Affirmative answers to the compulsive medication use questions were uncommon, ranging from 0–6.4%. The sole patient who met criteria for compulsive medication use endorsed both the introductory question and the most commonly-endorsed of the other four questions.

Combining disorders/behaviors—As some patients were diagnosed with more than one ICD but did not endorse questions on the QUIP for all diagnosed ICDs, we assessed the validity of a positive response for *any* ICD (using the aforementioned cutoff points) to identify an individual with *any* ≥ 1 ICD (as opposed to examining each individual ICD). This analysis had AUC=0.88 (sensitivity=0.97, specificity=0.79, PPV=0.53, and NPV=0.99).

Similarly, as some patients were diagnosed with more than one ICD or other compulsive behavior but did not endorse questions on the QUIP for each diagnosed disorder or behavior, we assessed the validity of a positive response for *any* ICD or other compulsive behavior (using the aforementioned cutoff points) to identify an individual with *any* ≥ 1 ICD or other compulsive behavior (compulsive medication use excepted). This analysis had AUC=0.85 (sensitivity=0.96, specificity=0.73, PPV=0.62, and NPV=0.98).

QUIP-S

Item Selection—To evaluate a shortened version of the ICD section, we started with the introductory question for each ICD and added questions only if they increased the sensitivity of the instrument. As a result, the abbreviated ICD section has 2 questions for each disorder (8 total questions; Table 4). The optimal cutoff point for each ICD was ≥ 1 affirmative answer

to any question, which led to similar AUCs, sensitivities, and specificities as the full ICD section.

The complete QUIP-S, created based on the results mentioned above, consists of two questions for each of the four ICDs, the three introductory questions for other compulsive behaviors, and the two questions for compulsive medication use endorsed by the sole patient who met diagnostic criteria (for a total of 13 questions). A single positive response to any disorder's/behavior's question is a positive screen for that disorder or behavior.

Combining disorders/behaviors—As we did for the QUIP, we assessed the validity of a positive response for *any* ICD (using the aforementioned optimal cutoff points of ≥ 1 affirmative answer) in the QUIP-S ICD section to identify an individual with *any* ≥ 1 ICD (as opposed to examining each individual ICD). This analysis had AUC=0.89 (sensitivity=1.00, specificity=0.79, PPV=0.53, and NPV=1.00).

We also assessed the validity of a positive response for any ICD or other compulsive behavior on the QUIP-S to identify an individual with *any* ≥ 1 ICD or other compulsive behavior (with the exception of compulsive medication). This analysis had AUC=0.83 (sensitivity=0.94, specificity=0.72, PPV=0.61, and NPV=0.96).

DISCUSSION

We found that the QUIP, a brief, self-completed screening questionnaire for ICDs and other compulsive behaviors in PD, has good discriminant validity using formal diagnostic criteria as the “gold standard” diagnosis.

To our knowledge, this is the first instrument to be developed and have score performance supporting validity as a screening instrument for the range of ICDs and other compulsive behaviors reported in PD. The Minnesota Impulsive Disorders Interview (MIDI)(22), which includes sections for compulsive gambling, sexual behavior, and buying, has been used in PD (4;17). However, the MIDI does not cover compulsive eating or other compulsive behaviors, and thresholding of scores to identify cases has varied across studies. Different rating scales (e.g., the South Oaks Gambling Screen(25)), questionnaires (Punding Questionnaire(20)), and diagnostic criteria (DSM-IV diagnostic criteria for pathological gambling, McElroy criteria for compulsive buying(26), Voon criteria for compulsive sexual behavior)(6), and descriptions of other compulsive behaviors(19;27) have either been used(3;5;17;28–30) or created for use (6;19;20;27) in PD, but no existing single instrument fulfills the criteria of being comprehensive, self-rated, and validated for use in this population.

The ICD section of the QUIP had at least 80% sensitivity and specificity for each of the 4 ICDs at the recommended cut-off points. As ICDs were frequently co-morbid but not always co-endorsed, combining the four ICDs increased the sensitivity for identifying an individual with any ICD to 97%. Thus, in many cases, ICD patients who failed to screen positive for one ICD were still identified with a positive screen for another ICD.

The sensitivity and specificity for the hobbyism subsection were both $>90\%$. The instrument was limited in sensitivity for the punding and walkabout subsections (60–65%). However, interpretation of the walkabout results was limited by the low number of cases. Furthermore, the full meaning and range of behaviors associated with punding were difficult to convey and capture in a brief questionnaire. Combining the ICD section and the other compulsive behaviors sections increased the sensitivity for identifying an individual with any disorder/behavior to 96%.

On post hoc analysis we found that the psychometric properties for each ICD in the QUIP-S were similar to their counterparts in the QUIP. Additionally, the QUIP-S ICD section overall had a sensitivity of 100% for identifying a patient with at least one ICD, and the total QUIP-S had a sensitivity of 94% for identifying a patient with at least one ICD or other compulsive behavior.

The median completion time for the QUIP (30 questions total) was 5 minutes. We estimate that the median completion time for the QUIP-S (13 questions total) is 3 minutes. Although the shortened version was not formally tested, we do recommend it for routine use as the specific questions and overall structure of the instrument were not modified in any way. Clinicians or clinical researchers who want the additional information provided by the full questionnaire may choose to administer this version.

The QUIP was designed and validated as a screening instrument, not as a diagnostic or rating instrument. The negative predictive values (NPVs) for each ICD were very high, so a negative screen appears to signal with a great degree of certainty that an ICD is not present. For a screening instrument, a high NPV is crucial, while a low PPV can be counterbalanced by conducting a follow-up clinical interview.

Positive predictive values (PPVs) were low overall, indicating that a positive screen needs to be followed by a clinical interview to verify if the patient truly has clinically significant ICD or other compulsive behaviors. Since ICDs and other compulsive behaviors are commonly comorbid, patients in particular who screen positive for a single ICD should be queried about the range of ICDs and other compulsive behaviors reported in PD.

The low PPVs for most of the ICDs and other compulsive behaviors are in part a reflection of the relatively low frequency of each disorder in our study population (the most common behavior, hobbyism, was diagnosed in <15% of patients). In addition, there are other reasons a patient might endorse symptoms on the QUIP but not meet diagnostic criteria for an ICD or other compulsive behavior when interviewed. First, ICDs or other compulsive behaviors may be present at subsyndromal levels, in which case follow-up and monitoring is appropriate as such patients may be at higher risk of developing a disorder (i.e., having symptoms that lead to distress or some form of psychosocial impairment). Similarly, a clinician might consider the presence of subsyndromal symptoms in therapeutic decisions for a given patient, such as whether to utilize a DA or levodopa. Second, a patient may acknowledge symptoms leading to a positive screen with the QUIP, but minimize symptom severity on formal interview leading to a negative diagnostic interview. An example from clinical experience are married male patients who acknowledge compulsive sexual behaviors, but report them as not being clinically significant, whereas the spouse will report that such symptoms are causing distress or impairment in the marital relationship. This situation highlights the value of including an informed other, if available, when clinically evaluating the significance of ICD and other compulsive behaviors. Third, the diagnostic criteria used for the different disorders for the validation process may have imposed a limitation. Pathological gambling has arguably the most well-established diagnostic criteria(1), and the QUIP had the highest PPV for this disorder. The lowest PPVs were for compulsive buying and eating, disorders for which it may be difficult to differentiate pathological behaviors from excessive behaviors that do not rise to the level of a disorder. Finally, a patient may be more willing to endorse symptoms on a self-administered questionnaire than to an interviewer.

There are several limitations to note. First, the diagnostic criteria for two of the disorders and behaviors (i.e., binge-eating disorder and walkabout) were slightly modified to be consistent with clinical experience. Second, only one patient met diagnostic criteria for compulsive medication use thus limiting validation of this section of the questionnaire, and less than 10

subjects each had compulsive eating or walkabout. Third, as we used a time frame of “anytime during PD” to assess ICD and other compulsive behaviors, recall bias may have influenced the accuracy of the information provided. Fourth, as our study population was a convenience sample of PD patients, we cannot say if the instrument would have performed differently in a random sample of patients. Finally, as a result of providing many examples and using terms from existing instruments, the QUIP is rated at a 12th grade reading level, and it is unknown how this would affect the screening of PD patients with less than 12 years of formal education.

Both the QUIP and QUIP-S are appropriate for use in clinical care and clinical research as screening instruments for the range of ICDs and other compulsive behaviors reported in PD. Future studies should include a larger number of patients with a range of ICD histories to validate our preliminary findings. In addition, the QUIP should be tested in other populations who may be at risk for ICD development (e.g., restless leg syndrome [RLS] patients receiving DA therapy(31)).

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Demographic and clinical characteristics

Variable	Mean (SD) or % (N)
Age (# years)	65 (9.4)
Sex (% male)	75% (118)
Race (% white)	95% (149)
Education (# years)	15.4 (3.0)
PD duration (# years)	9.0 (6.3)
Hoehn & Yahr stage (median)	2.0
Levodopa dosage (mg/day)	618 (434)
Dopamine agonist use (% yes)	59% (93)
History of deep brain stimulation (DBS; % yes)	20% (32)
Self-report history of bipolar disorder (% yes)	0

Table 2

Validation of the QUIP ICD section by disorder

	Cutoff Points ^a																			
	Gambling (N=11)					Sex (N=14)					Buying (N=10)					Eating (N=7)				
	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5	1	2	3	4	5
Sensitivity	91	91	82	64	46	100	86	71	50	43	80	60	40	30	30	86	86	57	43	29
Specificity	94	97	99	99	100	89	93	98	98	99	89	97	99	99	100	83	89	94	98	99
PPV	53	71	90	88	100	47	55	77	70	86	33	55	67	75	100	19	26	31	50	67
NPV	99	99	99	97	96	100	99	97	95	95	98	97	96	95	95	99	99	98	97	97
AUC (95% CI)	.95 (.85-1.05)					.97 (.95-1.00)					.87 (.72-1.02)					.88 (.72-1.04)				

^aFive questions per ICD

Table 3

Validation of other compulsive behaviors

	Introductory Questions		
	Hobbyism (N=23)	Punding (N=16)	Walkabout (N=5)
Sensitivity	96	63	60
Specificity	90	93	97
PPV	61	50	43
NPV	99	96	99
AUC (95% CI)	.93 (.87-.98)	.78 (.63-.92)	.79 (.52-1.05)

Table 4

Validation of QUIP-S ICD section by disorder

	Cutoff Points ^a							
	Gambling ^b (N=11)		Sex ^c (N=14)		Buying ^d (N=10)		Eating ^e (N=7)	
	1	2	1	2	1	2	1	2
Sensitivity	91	73	100	64	80	40	86	43
Specificity	95	99	90	96	91	99	85	96
PPV	59	89	48	60	38	80	21	40
NPV	99	98	100	96	99	96	99	98
AUC (95% CI)	.95 (.84–1.05)		.96 (.93–.99)		.87 (.72–1.02)		.88 (.72–1.04)	

^aTwo questions per ICD

^bQuestions #1 and 4

^cQuestions #1 and 2

^dQuestions #1 and 5

^eQuestions #1 and 3