



# First assessment of the validity of the only diagnostic criteria for postorgasmic illness syndrome (POIS)

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## Abstract

Postorgasmic illness syndrome (POIS) is a rare condition that affects men and about which little is known. According to Waldinger and colleagues, men with POIS fulfill three or more of five preliminary diagnostic criteria regarding symptoms, time to onset, setting, duration, and spontaneous disappearance. We conducted a self-report study to assess, for the first time, the validity of these criteria. One hundred and twenty-seven men with self-reported POIS have completed the survey, making this the largest study of such men to date. Almost all respondents fulfill a majority of the criteria for POIS; a large minority fulfills all five criteria. Almost all respondents always experience symptoms after ejaculating in at least one ejaculatory setting (sex, masturbation, or nocturnal emission), though only a small majority fulfill the criterion that symptoms occur after all ejaculations because a large minority always experience symptoms in one setting but not always in another. The most common symptom cluster from the criteria, involving fatigue, irritation, and concentration difficulties, is always experienced by 80% of respondents. Median symptom severity is 8 on a 0–10 scale. While almost all men with POIS fulfill a majority of the preliminary diagnostic criteria, there is room for refining some of the criteria.

## Introduction

In 2002, Waldinger and Schweitzer introduced the term “postorgasmic illness syndrome (POIS)” and described the first two cases of POIS in the medical literature [1]. POIS is a rare [2] sex-related condition that affects men and, in very rare cases, according to Waldinger, also affects women [3]. It is not well understood [2]—there are different hypotheses about its etiology [4–7] and there is no accepted effective treatment [2, 8]. There are a small number of case reports in the literature [1, 5–7, 9–12], as well as case reports and an editorial discussing similar symptoms that do not use the term “POIS” [13–15]. These reports are from the United Kingdom, Egypt, Spain, China, Korea, Colombia, the Netherlands, and India. Besides these, there is only one study that involves >2 individuals—the study of 57 Dutch men with POIS [4]. In that paper, Waldinger and colleagues

use 12 men to develop a preliminary diagnostic criteria and study 45 men who fulfill most of these criteria.

Men with POIS are thought to fulfill “most” of the preliminary diagnostic criteria, “indicating that the presentation of POIS, albeit variable, is quite well represented by these criteria” [4]. Waldinger’s preliminary diagnostic criteria (WPDC) are as follows: [3]

1. One or more symptoms from among these seven symptom clusters:
  - General cluster: extreme fatigue, exhausted, palpitations, problems finding words, incoherent speech, dysarthria, concentration difficulties, quickly irritated, cannot stand noise, photophobia, depressed mood.
  - Flu-like cluster: feverish, extreme warmth, perspiration, shivery, ill with flu, feeling sick, feeling cold.
  - Head cluster: headache, foggy feeling in the head, heavy feeling in the head.
  - Eyes cluster: burning, red injected eyes, blurred vision, watery, irritating, itching eyes, painful eyes.
  - Nose cluster: congested nose, watery, runny nose, sneezing.

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- Throat cluster: dirty taste in mouth, dry mouth, sore throat, tickling cough, hoarse voice.
  - Muscle cluster: muscle tension in back or neck, muscle weakness, painful muscles, heavy legs, stiffness in muscles.
2. Symptoms begin from within a few seconds to within a few hours after ejaculation that occurs during coitus, masturbation, or nocturnal emission.
  3. Symptoms occur after all or almost all ejaculations.
  4. Most symptoms last for about 2–7 days.
  5. Symptoms disappear spontaneously, that is, without treatment.

This exploratory analysis assesses for the first time the validity of WPDC, the only diagnostic criteria for POIS. To do this, and to better understand POIS, we are conducting a self-report study of internet forum users who report having POIS (“the POIS Survey”). Data from the POIS Survey will be publicly available at <https://sites.google.com/view/the-pois-survey>, facilitating further research of the syndrome. This is the first publicly available survey data on POIS.

## Methods

The POIS Survey, an anonymous self-report study, was launched in the Fall of 2018 and is being conducted online, in English. Respondents affirm that they are aged  $\geq 18$  years and consent to all the information that they provide being made public. No personally identifiable information is collected. Ethical & Independent Review Services reviewed the protocol and determined that no IRB review is required (E&I Assigned Study ID: 18173–01).

Because there is no known effective treatment for POIS, many individuals with POIS-related complaints seek out information in internet forums. We identified three English-language internet forums devoted to POIS<sup>1</sup> and invited forum participants to take the survey. Forum administrators promoted the survey as well. Respondents are not compensated.

Prior to launch, the survey was pilot tested—forum participants took draft versions of the survey and anonymously discussed them on the forums. Survey questions were reworded to address ambiguity. Items about aspects of the condition that forum participants thought were important were added. For instance, since forum participants

seemed to agree that their symptoms are generally severe, questions about symptom severity were added.

The three POIS forums have a total of approximately 1200 subscriptions. Because many individuals (21% among the respondents analyzed in this paper) are subscribed to more than one of the forums, the total number of individuals subscribed is less than the total subscription count of 1200. It is not known how many subscribers are inactive and therefore would not have seen the survey invitation.

Only males aged  $\geq 18$  years who reported that they have POIS are analyzed in this paper; men who reported that they do not have POIS or that they are not sure whether they have POIS are excluded. Though female respondents are excluded from this analysis, note that two female respondents reported that they have been diagnosed with POIS by a medical doctor or another healthcare provider.

## Waldinger’s preliminary diagnostic criteria

To decide whether a respondent fulfills a particular criterion, we operationalize WPDC as follows. A respondent is counted as fulfilling Criterion 1 if there is at least one symptom cluster from which he (almost) always experiences symptoms during his POIS attacks.

For Criterion 2, we interpret “a few hours” as 6 h. This interpretation is consistent with [4], in which 98% of POIS patients had a time to onset of  $\leq 4$  h.

The survey asks about symptoms after ejaculating in three different settings—the three settings that are explicitly stated in Criterion 2: sexual intercourse, masturbation, and nocturnal emission. A respondent is counted as fulfilling Criterion 3 if he reports that, for each setting, he either (almost) always has symptoms after ejaculating or he has not been in that setting in the 6 months prior to taking the survey. Responding that he has not been in any of the settings in the past 6 months would be ambiguous, and no respondent responded in this way. We limit the question to the past 6 months to make sure that respondents accurately remember whether they have symptoms in each setting.

For Criterion 4, we interpret “about 2–7 days” as between 1 and 10 days. Since there is no known treatment for POIS, Criterion 5 is operationalized as duration of POIS attacks being  $\leq 21$  days; a longer duration could just indicate that the symptoms are chronic, which would contradict the idea that POIS attacks are acute events.

## Symptom severity

In addition to questions directly related to WPDC, we also ask about symptom severity in four different domains: physical pain; interference of POIS symptoms with usual social activities or relationships with others; interference of POIS symptoms with work or school; and interference of

<sup>1</sup> The forums are: the POIS forum on Reddit <https://www.reddit.com/r/POIS/>; the POIS Center forum <https://poiscenter.com/forums/index.php>; and the Post Orgasmic Illness Syndrome (POIS) Facebook group <https://www.facebook.com/groups/1457009341209480/>. The last two forums are listed by [2].

POIS symptoms with activities of daily living, such as dressing/bathing, eating, walking/moving about, toileting, and hygiene. Severity is reported on a 0–10 point scale based on [16], with 0 being “No symptoms” and 10 being “Symptoms are so excruciating that nothing else matters.” We define overall symptom severity as the maximum severity among these four domains.

Analysis

Data were analyzed in R [17]. Categorical variables are summarized using the percentage of individuals in each category. Quantitative variables are summarized using mean and standard deviation (SD), as well as median and interquartile range (IQR).

Results

At the time of this writing, 127 men who self-report having POIS have completed the survey. Of these, 20% report that they have been diagnosed with POIS by a medical doctor or another healthcare provider. One of the respondents was studied in [4]. Thus, considering the current paper and [4], there are 183 (= 127 + 57 – 1) men with POIS who have been studied in the medical literature, in addition to the several men described in the case reports.

Demographics are given in Table 1. The survey is conducted in English, in which all the respondents are proficient. In addition, some respondents are proficient in at least one other language, namely, Arabic, Chinese (simplified and traditional), Croatian, Danish, Dutch, French, German, Hindi, Italian, Polish, Portuguese, Russian, or Spanish.

The percentage of men who fulfill a particular number of WPDC is shown in Table 2. While 97% of men fulfill ≥3 criteria, and thus are considered to have POIS under WPDC, only 39% fulfill all 5 criteria.

Table 1 Characteristics of men with POIS

|  |             |
|--|-------------|
| Age, years                                     |             |
| Mean (SD)                                      | 34 (12)     |
| Median (IQR)                                   | 30 (25, 40) |
| Marital status, %                              |             |
| Married  | 27          |
| Partner, living together                       | 9           |
| Partner, not living together                   | 10          |
| Divorced                                       | 2           |
| Single   | 51          |
| Proficient in a language other than English, % | 25          |

IQR interquartile range, POIS postorgasmic illness syndrome

The criterion fulfilled by the fewest respondents is Criterion 3, regarding the setting in which symptoms occur. In all, 98% of men always experience symptoms after ejaculating in at least one ejaculatory setting (sex, masturbation, or nocturnal emission). The reason that many men do not fulfill Criterion 3 is that, while they always experience symptoms after ejaculating in one setting, they do not always experience them after ejaculating in another setting. In the 6 months prior to taking the survey, 44% of men ejaculated in two or three ejaculatory settings and in at least one of them did not always experience symptoms. Specifically, 17% of respondents both masturbated and had nocturnal emissions in the 6 months prior to taking the survey, always had symptoms after masturbation, but either did not have symptoms or are not sure if they had symptoms after nocturnal emissions. Likewise, 13% both had sex and nocturnal emissions, always had symptoms after sex, but either did not have or are not sure if they had symptoms after nocturnal emissions.

Table 2 shows the number of men who experience symptoms from each of the symptom clusters of Criterion 1. The General and Head clusters are the only ones that are experienced always by more than half the respondents. The Nose and Throat clusters are experienced always or occasionally by less than half of the men.

Table 3 shows symptom severity. Overall symptom severity is high—IQR is from 7 (“Symptoms are focus of attention. They prevent me from typical daily activities.”) to 9 (“Symptoms are unbearable. I am unable to do anything.”).

Discussion

This first assessment of the validity of the only diagnostic criteria for POIS finds that almost all men with self-reported POIS do fulfill a majority of the criteria and thus have POIS according to the criteria, while a large minority of them fulfill all five criteria.

Because symptoms are so varied and there does not appear to be a single symptom cluster that defines POIS, a possible refinement of Criterion 1 could be to consider not just the symptoms themselves but also symptom severity, which is typically high.

A large minority of men with self-reported POIS do not fulfill Criterion 3 because they do not always experience symptoms in one of the ejaculatory settings. The fact that some men always have symptoms after, for example, masturbation or sex but not after nocturnal emissions could be an important clue about the etiology of their disease. A possible improvement of Criterion 3 could be to amend it to “In at least one ejaculatory setting (sex, masturbation, or

**Table 2** Fulfillment of preliminary diagnostic criteria for POIS

| Fulfill this many criteria                   | %                              |   |  |
|--|--------------------------------|---|--|
| 0  | 0                              |   |  |
| 1  | 2                              |   |  |
| 2  | 2                              |   |  |
| 3  | 12                             |   |  |
| 4  | 46                             |   |  |
| 5  | 39                             |   |  |
| <b>Fulfill this criterion</b>                | <b>%</b>                       |   |  |
| Criterion 1: symptom clusters                | 91                             |   |  |
| Criterion 2: time to onset                   | 88                             |   |  |
| Criterion 3: setting                         | 56                             |   |  |
| Criterion 4: duration                        | 88                             |   |  |
| Criterion 5: spontaneous disappearance       | 95                             |   |  |
| <b>In the past 6 months, in this setting</b> | <b>Have not ejaculated (%)</b> | <b>Ejaculated and always had POIS attacks after (%)</b> | <b>Ejaculated but did not always have POIS attacks after (%)</b> |
| Sex  | 17                             | 65  | 18   |
| Masturbation                                 | 0                              | 96  | 4  |
| Nocturnal emission                           | 18                             | 46  | 36   |
| <b>Symptom cluster</b>                       | <b>Always (%)</b>              | <b>Always or occasional (%)</b>                         |  |
| General                                      | 80                             | 92  |  |
| Head   | 54                             | 74  |  |
| Muscle                                       | 49                             | 68  |  |
| Eye  | 35                             | 58  |  |
| Flu  | 32                             | 63  |  |
| Nose   | 28                             | 46  |  |
| Throat                                       | 24                             | 42  |  |
| <b>POIS attacks</b>                          | <b>Mean (SD)</b>               | <b>Median (IQR)</b>                                     |  |
| Time to onset (hours)                        | 4.3 (12.5)                     | 0.5 (0.0, 2.0)  |  |
| Duration (days)                              | 5.0 (3.6)                      | 4.0 (3.0, 6.0)  |  |

*IQR* interquartile range, *POIS* postorgasmic illness syndrome

**Table 3** Symptom severity (0–10 scale)

|                                     | Mean (SD) | Median (IQR) |
|-------------------------------------|-----------|--------------|
| Physical pain                       | 5.5 (3.0) | 6 (3.5, 8)   |
| Interference with social activities | 7.3 (1.3) | 7 (6, 8)     |
| Interference with work              | 7.1 (1.6) | 7 (6, 8)     |
| Interference with ADLs              | 5.1 (2.3) | 5 (4, 7)     |
| Overall                             | 7.8 (1.3) | 8 (7, 9)     |

*ADL* activity of daily living, *IQR* interquartile range

nocturnal emission), symptoms occur after all or almost all ejaculations.”

Men with self-reported POIS speak many different languages, which, along with the fact that the case reports are

from around the world, implies that POIS is likely not a culture-bound syndrome. Not only does POIS affect men from around the world, it affects men of various ages and relationship statuses. We find support for the previous finding of Waldinger [3] that POIS might affect women as well.

Because this self-report study is conducted online, it allows gathering data from a lot more individuals than a clinical study. This is especially important for researching a rare condition such as POIS. Indeed, this is the largest study of men with POIS thus far. Unlike in previous studies, study participants are from all over the world. Survey data will be publicly available, facilitating further research into POIS.

This study also has important limitations. The major limitation is that respondents were not examined by a

clinician to verify their answers, which highly contrasts with a clinical setting study, such as Waldinger et al. [4].

Since some preliminary diagnostic criteria are not exact, we operationalize them using specific values. For Criterion 2, we interpret “a few hours,” as originally stated by Waldinger et al. [4], as 6 h; and for Criterion 4, we interpret “about 2–7 days” as 1–10 days. We do realize that Waldinger et al. [4] thoughtfully used the terms “a few hours” and “about 2–7 days,” as a study focusing on the latency time after ejaculation or symptom duration was not at hand at the time they formulated these criteria. It might therefore well be that POIS symptoms may also become clinically manifest after a latency time of 6 h, might last >7 days, or last <2 days.

If we had operationalized the criteria using different values, the percentages of respondents who fulfill them would have been somewhat different as well. The focus of this study is not the exact percentage of respondents who fulfill each criterion but whether these percentages are high or low.

Other limitations of the current study are:

- We added a time restriction to Criterion 3, hereby changing the wording of Criterion 3 as originally suggested by Waldinger et al. [4], who did not make a time restriction in this criterion.
- Because it is not known how many people saw the survey invitation, response rate is not known.
- While survey respondents are from all over the world, the survey is in English, which limits the sample to people proficient in English.

Almost all men with self-reported POIS fulfill a majority of the preliminary diagnostic criteria for POIS. However, only a minority fulfill all five criteria, and there is room for refining some of the criteria. POIS affects men from around the world, of various ages and relationship statuses, and might even affect women.

## Disclaimer

Alex Strashny wrote this paper in his personal capacity. The views expressed are his own and do not represent the views of the Centers for Disease Control and Prevention.

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## Compliance with ethical standards

**Conflict of interest** The author declares that he has no conflict of interest.

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