

Sylvia v. Mackensen

Institute of Medical Psychology, University Medical Centre, Hamburg, Germany

Introduction

- In medicine, compliance or adherence describes the degree to which a patient correctly follows medical advice.
- The WHO defines adherence as **“the extent to which a person's behaviour (taking medication, following a diet, executing lifestyle changes) corresponds with agreed recommendations from a healthcare provider.”**
- Most commonly, it refers to medication or drug compliance, but it can also apply to other situations such as medical device use, self-care, self-directed exercises or therapy sessions.
- Adherence has a great impact on the health condition of haemophilia patients. Non-adherence to haemophilia treatment limit treatment efficacy and contribute to suboptimal prevention of bleeding.
- Different factors are known to affect adherence such as social/economic, therapy-related, patient-related, condition-related and health system-related factors.
- Potential barriers to adherence exist such as time-constraints of infusions and lack of understanding of the disease.

Assessment of Adherence

- It is of utmost importance to evaluate treatment adherence in haemophilia patients and to verify which the possible barriers of those patients are in order to help them to overcome these barriers.
- For the adequate assessment of adherence in haemophilia standardised and validated measures are necessary.
- Adherence can be measured via physician's or patient's report.
- Physician's reports are often based on a calculation of the percentage of usage of factor concentrate and prescription of factor concentrate.
- For patient reports different patient-rated outcomes (PROs) exist. Most PROs are generic measures:
 - BMQ = Brief Medication Questionnaire
 - MAQ = Medication Adherence Questionnaire (also known as the Morisky-4 or MMAS-4 scale)
 - MARS = Medication Adherence Rating Scale
 - SEAMS = Self-Efficacy for Appropriate Medication Use Scale
- Up to now only one published haemophilia-specific PRO exists:
 - VERITAS-PRO: Validated Hemophilia Regimen Treatment Adherence Scale—Prophylaxis
 - VERITAS-PRO is a self-/parent-report questionnaire consisting of 24 questions pertaining to six subscales
 - Time, Dose, Plan, Remember, Skip, Communicate

Studies into the Assessment of Adherence

1. US Study (du Treil et al., 2007)

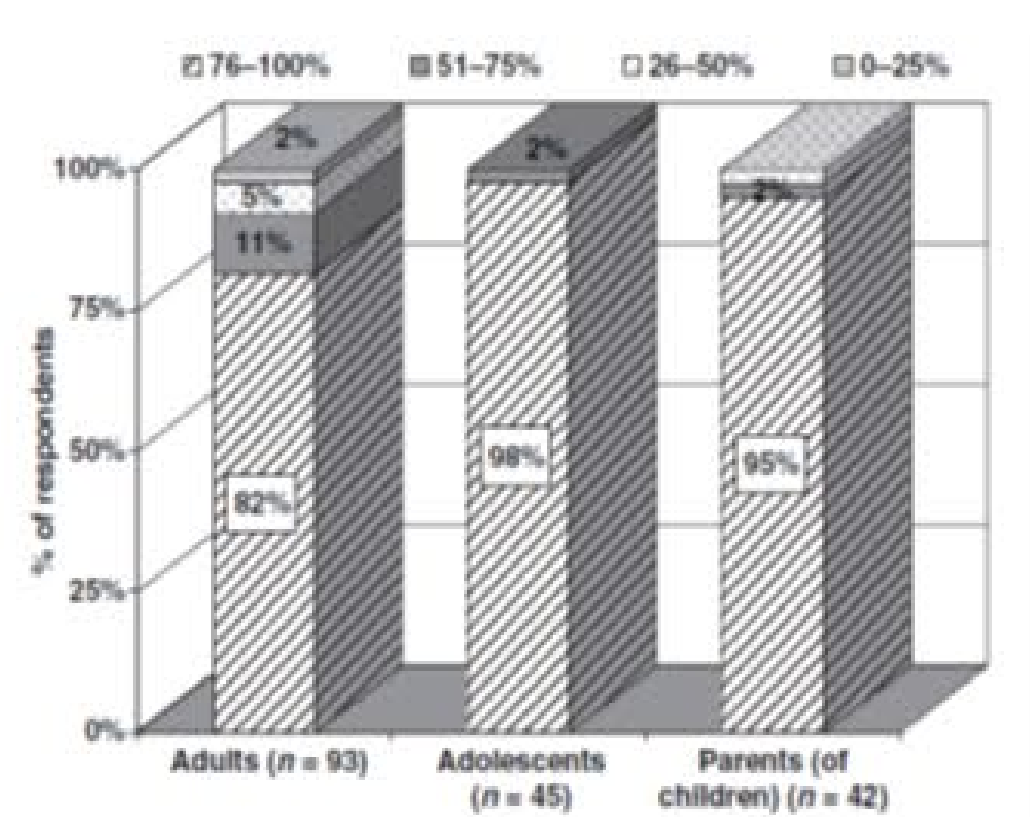
- 47 PWH (28 adults, 19 children)
- Adherence determination based on:
 - Physicians' recommendation
 - Patient infusion logs
 - Factor use
- <33 %: low adherence
- 34-66%: moderate adherence
- 67-100%: high adherence

Table 1. Number of adult and child subjects in each adherence category.

| | Low adherence | Moderate adherence | High adherence | Total |
|----------|---------------|--------------------|----------------|-----------|
| Adults | 5 (18%) | 12 (43%) | 11 (39%) | 28 (100%) |
| Children | 8 (42%) | 6 (32%) | 5 (26%) | 19 (100%) |
| Total | 13 (28%) | 18 (38%) | 16 (34%) | 47 (100%) |

2. European Study (De Moerloose et al., 2008)

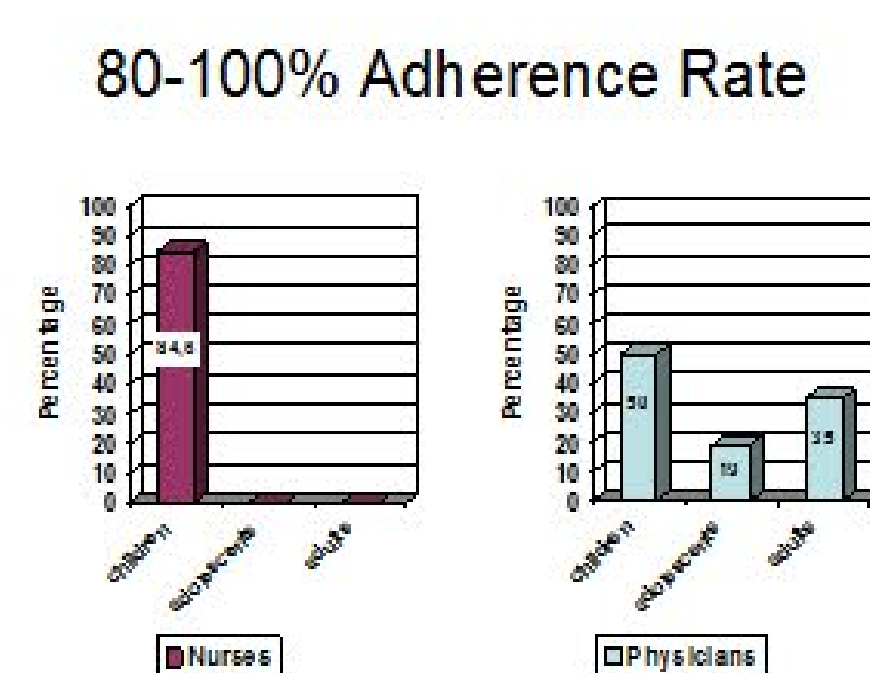
- 180 PWH from 6 European countries
- Level of adherence was defined as:
 - percentage of factor concentrate administered compared to the amount of concentrate prescribed.
- Two levels of adherence:
 - 0-75% and 76-100%.



Studies into the Assessment of Adherence

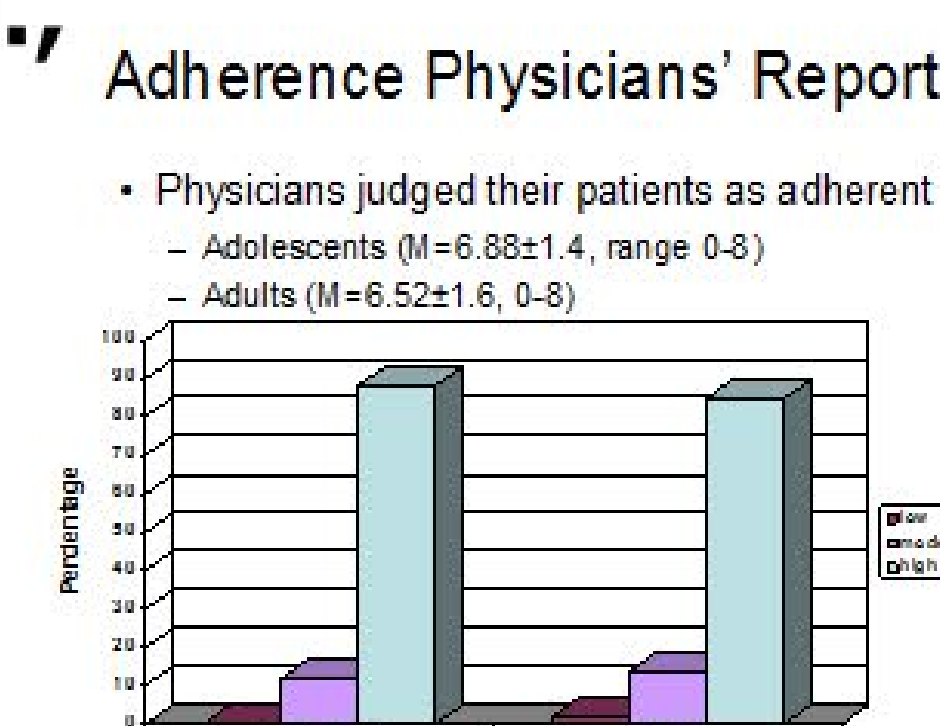
3. Canadian Study (Chan et al., 2011)

- 35 physicians and 17 nurses estimated the adherence rate of their patients:
 - children aged 0-12 years
 - adolescents aged 13-17 years
 - adults aged ≥ 18 years
- Patients were considered adherent:
 - Who comply with treatment/prophylaxis recommendations with minimal deviation and the proportion who comply with the request to maintain a diary with minimal deviation.



4. European Study (von Mackensen et al., 2012)

- 69 PWH from 7 European countries
- Level of adherence was assessed via self-report and physician-report
 - 85.7% of adolescents and 82.4% of adults reported to follow the prescribed treatment
 - 14.3% of adolescents and 2% of adults reported not to follow the prescribed treatment



Adherence Rates Across Different Studies

| Study | Country | Assessment of Adherence | High Adherence | Adolescents | Adults |
|---------------------------|---------|--|----------------|-------------|--------|
| Du Treil et al., 2007 | US | Recommendation Infusion logs Factor use | 67-100% | 26% | 39% |
| Moerloose et al., 2008 | Europe | Percentage factor administered/factor prescribed | 76-100% | 98% | 82% |
| Chan et al., 2011 | Canada | Comply treatment recommendation & comply request to maintain diary | 80-100% | 19% | 35% |
| v. Mackensen et al., 2012 | Europe | Check-up Factor prescription Diary/infusion log | 75-100% | 88.2% | 84.6% |

Conclusion

- Medical non-compliance has been identified as a major public health problem that imposes a considerable financial burden on modern healthcare systems.
- Poor compliance with a therapeutic regimen has a major impact on patients' clinical outcomes and might lead to physicians' frustration.
- Until now there has been no uniform way to evaluate adherence in haemophilia resulting in different adherence rates across studies. There is a need of a standardised and uniform way to evaluate adherence in haemophilia.
- Recently, a first haemophilia-specific, self-rated adherence questionnaire was developed, which is a first step to assess adherence in a standardised way.

References

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