Why do they keep coming back? Persistent frequent attenders in primary care
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general introduction

Background and motivation for this study

Every General Practitioner (GP) will recognize the slight confusion when the name of a patient that recently visited the practice several times, is again on the daily schedule: “A new appointment again? Didn’t we reach a conclusion last time? Did the complaints aggravate? Was the diagnosis and intervention (perceived as) insufficient?” Sometimes you feel you have fallen a bit short, annoyed or unable to think of a good explanation. And you may wonder whether there might be something in this patient that you did not recognize and, consequently, did not treat adequately, resulting in this repeated attendance. Patients who visit their GP much more often than other patients in the practice are called Frequent Attenders (FAs). In this thesis we describe (persistent) FAs and investigate factors leading to (persistence of) frequent attendance, relations with the wellbeing of these patients, treatment options for FAs and cost consequences.

Most patients only attend their GP frequently for a short period of time\textsuperscript{1-4} and only 20–30\% of FAs continues to attend frequently in the following year.\textsuperscript{1,3} FAs not only frequently attend their GP, but they are also more often referred to specialist care than non-frequent attenders (non-FAs).\textsuperscript{5} The burden on primary and secondary care of FAs is high. In the United Kingdom approximately 80\% of a GP’s clinical work is spent on 20\% of his/her patients, and this often leads to care that is not effective in helping the patient.\textsuperscript{6} Most short-term frequent attendance can adequately be explained, for example by a temporary medical problem. However, when frequent attendance spans more (consecutive) years both chronic physical and long-lasting psychosocial problems are often present in this group of patients.\textsuperscript{7-11} Psychological distress, low physical quality of life (QoL), and a low educational level are associated
Persistent frequent attendance may be considered an easily detectable type of behavior, indicating underlying psychosocial or psychiatric problems and low QoL, sometimes undetected and untreated.

Therefore, we concentrate this research on persistent frequent attendance. Because somatic problems are already adequately addressed in everyday GP-care and (chronic) care models, we more specifically focus on the role of psychological and social factors in the aetiology of (persistence of) frequent attendance. We think this approach might also contribute to the thoughtful design of preventive strategies for persistence of frequent attendance.

**Definition of (persistent) frequent attenders and how to select FAs in a normal GP’s practice?**

Several methods for selecting frequent attenders have been used until now.13,14 The older the patient, the more frequently he or she will visit healthcare professionals in primary and secondary care, just because of physical aging.15 Women of all age groups make more use of healthcare than men.11,16 Consultation frequencies differ between countries and, within countries, by GP.14 Just selecting the most attending persons thus will lead to the selection of predominantly older females and patients of a limited number of GPs. Hence, it is more appropriate to select the exceptional users *within every age and sex group of a GP (practice).*14 Such a proportional threshold definition selects the exceptional users compared to their peers and allows for meaningful comparison between individual practices, periods, and countries.

Therefore, in this thesis we define FAs as those patients whose attendance rate ranks in the top 10 centile per age and sex group in a GP-practice within a time frame of one year, and persistent FAs as those patients who are FA during three consecutive years. To calculate FAs we used all face-to-face consultations with GPs (consultations in the surgery and house-calls) and the number of all enlisted patients in a practice.

Selecting FAs by using age groups with a small range (for example a 10-year range) is difficult and labour-intensive, especially in smaller populations like those of a single practice. It may result in low numbers of patients in each age group. In the UK, Howe advised using the following method to define FAs: group all men and for women create two age groups and calculate the top 10% attenders in each of these three groups.13 To establish which method would be most appropriate and feasible to use in the Netherlands, we tested different methods of selecting FAs in an average general (group) practice (Chapter 2).
How to understand and interpret frequent attendance?

To structure our research we hypothesized that within the context of a given western GP-centred primary healthcare system, attendance rates may be influenced by patient characteristics (including morbidity), by GP characteristics (like work style, experience, personality and professional interests), and thirdly by the interpersonal dynamics between patients and their physicians (see figure 1). We restrict our scope to healthcare systems with a well-organized primary care in which GPs provide continuity of care for enlisted patients and act as gatekeepers to specialist care.

Patient characteristics

Most studies describing patient characteristics concern short-term frequent attenders. The decision whether to consult a GP seems to depend on the patient’s past experience with healthcare, the perception of the symptoms, the perception of the GP’s role as well as the relationship with the GP.\textsuperscript{17-20} Other reported factors are health anxiety (balancing fears), passivity, lack of control or mastery and mental health problems.\textsuperscript{20} One study found that FAs are often not aware of their frequent attendance. The interviewed patients regarded the GP as an appropriate figure to solve their distinctive and multiple physical symptoms and, despite their trust in the GP, some dissatisfaction with the (not) given treatment remained.\textsuperscript{21}

FAs with medically unexplained symptoms (MUS) seem to persist in frequent attendance because of high health anxiety and concern about a missed diagnosis, often despite some level of insight in their condition.\textsuperscript{19} In the attachment theory cognitive schemas based on earlier repeated experiences with caregivers are considered to influence how individuals perceive and act within interpersonal relationships. The ‘insecure attachment style’ was shown to be associated with frequent attendance after adjusting for socio-demographic characteristics, presence of chronic physical illness and baseline physical function. The ‘preoccupied attachment style’ was associated with high primary care costs and utilization.\textsuperscript{22,23} These associations were particularly strong for those patients who believed that a physical problem caused their unexplained symptoms. High consultation rates may be conceptualized as pathological care-seeking behaviour linked to insecure attachment.\textsuperscript{21} Understanding frequent attendance as driven by difficulties in relating to care giving figures may help doctors to manage their frequently attending patients in a different way. Other authors observed that attendance rates depend on early child experiences and that families tend to be consistent in illness and consultation patterns over the years and even over the generations.\textsuperscript{17,18,24,25}
Figure 1. Theoretical model of possible aetiological explanations of persistence of Frequent attendance.
**GP determinants**

It seems plausible that GPs also play a role in the attendance frequency of their patients. Physicians differ significantly in their clinical decision-making. The mean consultation frequency, but also the number of lab tests and referrals to secondary care vary considerably between GPs and practices.\(^{26,27}\) However, little is known about the impact of GP specific determinants on the frequency of consultation and on persistent frequent attendance in some patients.\(^{28}\)

A qualitative study described the emotions and thoughts of physicians at primary healthcare centers in Spain during consultations with short-term frequent attenders.\(^{29}\) Positive emotions regarding FAs were associated with young age of the physician and presence of the thought “This patient really needs me”. Feelings of lack of control were associated with working in rural centres and with negative thoughts about FAs. Anxious thoughts of the GP were associated with greater workload, more requests for tests, more requests to see the doctor outside regular hours, and negative thoughts about FAs. Guilt feelings were associated with a lower perceived ability to solve the patient’s problem, and with a poor physician-patient relationship. Sadness of the GP was associated with more frequent referrals to specialists.\(^{29}\)

**Interaction between patient and GP**

In the 1980s, some authors postulated that inadequate interpersonal dynamics between patients and their GP could cause more inappropriate and unnecessary consultations, testing and treatments, a phenomenon then labelled as “somatic fixation”.\(^{30-32}\) They emphasized the importance of adequate communication skills of the GP to break the chain of this fixation. However, literature describing the interaction between FAs and the GP is scarce.\(^{29}\)

**(Medical) problems of frequent attenders**

Most literature on FAs originates from countries which organise primary care through a system in which a primary care physician (e.g. a GP) serves a fixed group of enlisted patients. Apparently, frequent attendance is considered more of a problem in this healthcare system because payment of the GP is (largely) per enlisted patient and less per consultation. Several reviews from Scandinavian countries\(^{34}\), the United Kingdom\(^{33}\), Spain\(^{14}\) and Health Maintenance Organizations (HMO) in the United States\(^{35,36}\) describe morbidity of FAs during a one year period (1yFAs). In 1yFAs combinations of somatic and psychosocial problems are often observed and high rates of both psychological distress and psychiatric disorders are found.\(^{37-39}\) Rates of somatization among FAs vary between 16 and 45%.\(^{35,40,41}\) As far as we know there is only one study describing frequent
attendance in the Netherlands and only one study from a country with an open access system for primary care (France). The latter found that, when adjusting for confounders, among four psychiatric diagnoses investigated, only somatoform disorders remained significantly associated with frequent attendance. Physical health and chronic diseases were not associated with frequent attendance. Thus, 1yFAs suffer more often from chronic somatic diseases, medically unexplained symptoms, psychiatric problems (e.g. depression, anxiety) and social problems than non-FAs. Less is known about persistent FAs, but existing evidence indicates that these patients not only suffer from more somatic, but, in particular, from more psychiatric problems. FAs who are depressed are more likely to continue to be high-utilizers than non-depressed FAs. Therefore, we examined the somatic and psychosocial morbidity of (persistent) frequent attenders.

**Workload and costs of FAs in primary and specialist healthcare**

FAs are more frequently referred by their GP to specialist care than non-frequent attenders (non-FAs). However, little is known about the magnitude of the differences in primary and specialist healthcare utilisation and costs between non-FAs and FAs, as well as between subgroups of FAs (short-term versus persistent FAs). Differences in workload and healthcare costs may be explained by the specific characteristics and morbidities of FAs, and by physician characteristics. If not, detection and treatment of underlying, not yet detected, conditions in FAs may result in less morbidity, a better quality of life and decrease in costs.

Therefore, we examined the workload caused by FAs in primary care and costs of healthcare of (persistent) FAs in primary and specialist care and whether these costs can be explained by patients’ morbidities and by GP characteristics (chapter 3 and 6).

**Prediction of persistent frequent attendance**

Development of effective interventions to prevent 1yFAs to become persistent or repetitive FAs is only possible if knowledge is available about determinants that predict which one-year FAs are likely to become persistent FAs. However, literature about determinants that predict persistent frequent attendance is inconsistent and its interpretation is hampered by methodological differences (e.g. aetiological and causal versus predictive non-causal outlooks, or confusion of these two), and by different definitions of frequent attendance (e.g. proportional versus fixed cutoff). In prospective cohort studies, using a proportional definition (the upper 10%), low physical quality of life, low educational level and psychological distress (Hopkins Symptom Check List and Whiteley-7) predicted persistence of frequent
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Attendance over the next two consecutive years. Using a fixed cutoff definition of FA, one prospective cohort study found that female gender, obesity, former frequent attendance, fear of death, alcohol abstinence, low satisfaction, and irritable bowel syndrome were risk factors for persistence of frequent attendance during at least 3 out of the four next years. Another prospective cohort study concluded that the Ambulatory Diagnosis Groups “unstable chronic medical conditions”, “see and reassure conditions”, “minor time-limited psychosocial conditions”, and “minor signs and symptoms” predicted persistence of frequent primary care use the next year.

A prediction rule may help GPs to identify which 1yFA is at risk to become a persistent FA using information from the electronic medical record. Such a rule, in addition to being clinically important, may also support the selection of more homogeneous patient groups in future randomized trials among (subgroups of) persistent frequent attenders (chapter 4 and 5).

**Attempts to support and help (persistent) FAs, and to lower attendance rates**

Is it possible to reduce the morbidity and use of healthcare of FAs and to improve their quality of life? Several RCTs evaluating interventions for FAs have been published but a clear overview of the different kind of interventions, an assessment of their quality and the results of the interventions is lacking. Therefore, we reviewed the literature to determine possible positive interventions to improve the morbidity and the quality of life and to lower attendance rate of FAs (chapter 7).

This PhD thesis aims to answer these questions based on studies conducted among (persistent) frequent attenders in the Netherlands. Hereafter, the Persistent Frequent Attenders Risk Factors and treatment options (PERFACTIO) study is described and the structure of the thesis is outlined.

**The PERFACTIO study**

**Part I: Mapping frequent attenders in primary care**

The first objective of this thesis was to establish the best method for selecting FAs in a normal practice setting in the Netherlands. Secondly, we wanted to study morbidity and GP’s workload of FAs of different duration. Thirdly, we examined whether it would be feasible, using information readily available in GPs’ electronic medical records, to predict which 1yFAs continue to attend frequently and whether this prediction (rule) could be validated in another setting and timeframe. Finally, we examined the costs of healthcare utilization by FAs of different duration in primary and specialist care and to explore whether these costs could be explained by the excess morbidity these FAs have or the characteristics of the GP’s.
Research questions

1. What is the most feasible method to select FAs in a normal GP practice setting using the proportional definition? To answer this question we analysed in chapter 2 the data of the second Dutch National survey of General Practice. These data were collected over a one-year period on health and healthcare-related behaviour from 375,899 persons, registered within 104 practices. We compared the quality of different FA selection methods in general practice in the Netherlands.

2. Which somatic, psychological and social problems do (persistent) FAs have? What are the differences between short-term and persistent FAs in this respect? What is the workload of a GP caused by (persistent) FAs? In chapter 3 we analysed the GP database of the Academic Medical Center, University of Amsterdam (Hag-net-AMC) of three consecutive years cross-sectionally. We compared the diagnoses as registered by the GPs on the so-called Problem Lists of frequent attenders during none, one, two and three years, respectively.

3. Which readily available information noted by the GP in patients’ Electronic Medical Record predicts persistence of frequent attendance? In order to answer this question we performed in chapter 4 a historic three-year cohort study (2003-2005). We analysed which readily available data of 1yFAs out of the Electronic Medical Record of the GPs predict persistence of frequent attendance.

4. Can the prediction rule developed in chapter 4 be validated in another time frame in the same GP database and in another GP database? In chapter 5 we performed a geographical and temporal validation of our prior prediction rule with data of a GP network in Eindhoven, the Netherlands (SMILE; geographical validation) and our own network (Hag-net-AMC) in another time frame (2009-2011).

5. Are FAs of primary care also high users of specialist care? What are the costs of healthcare of FAs in primary and specialist care?

6. Are the high costs in primary and specialist healthcare of FAs of different duration associated with patient’s morbidities and GP characteristics? In order to answer research question 5 and 6 we linked in chapter 6 clinical data of primary care patients to financial reimbursement data of the main health insurer of our region (healthcare expenditures in primary and specialist care), and GP characteristics. In a multilevel regression model, we analysed
the healthcare expenditures of FAs and whether these expenditures can be explained by the morbidity of the patients and the characteristics of their GPs.

Part II: Review of the literature about interventions on frequent attenders in primary care.

7. Research question 7. To determine possible effective interventions to improve quality of life and lower attendance rate of FAs we systematically reviewed the literature about possible effective interventions in FAs in chapter 7.

Part III: A prospective study of frequent attenders

The objective of the prospective study was to better understand the causes of persistence of frequent attendance. This may facilitate the rational selection of diagnostic tests and (better) prevention strategies. Potentially effective interventions should be based on these aetiological factors for persistence of frequent attendance. Research question eight is:

8. Which (in particular psychosocial) factors are associated with persistence of frequent attendance in a prospective cohort of 1-year FAs? Is there a supra-additive effect of combinations of somatic, psychological and social factors? In order to answer these questions we conducted a prospective cohort study of 1yFAs and collected data about their GPs in chapter 8. With a multilevel regression analysis we evaluated which patient and GP characteristics are associated with persistence of frequent attendance.

Screening and consecutive treatment of patients in primary care tends to have disappointing results. Therefore, we extrapolated the findings from the cohort study among FAs over a period of 5 years and combined this with potential treatment effects using modelling techniques. Research question nine is:

9. To evaluate whether systematic detection and treatment of depression and anxiety after one or two years of frequent attendance may be cost-effective compared to usual GP care. Therefore we performed in chapter 9 a Cost Effectiveness Analysis (CEA) with data of the cohort of chapter eight. With a Markov simulation we analysed whether diagnosing and treating of depression and anxiety (as measured by the Patient Health Questionnaire) in FAs might be cost effective after one or two years of frequent attendance.

We end the thesis with chapter 10, which provides a general discussion and conclusion of our research.


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