Results of the 2012 Sentinella survey

Attention deficit/hyperactivity disorder in Swiss primary care

Alex Gamma^a, Andreas Müller^b, Gian Candrian^b, Dominique Eich^c

^a Department of Forensic Psychiatry, Institute of Forensic Medicine, University of Bern, Switzerland; ^b Brain and Trauma Foundation Grisons, Chur, Switzerland; ^c Psychiatric University Hospital, Division of ADHD Research, Zurich, Switzerland

Summary

In 2012, the "Sentinella" survey of Swiss primary care physicians (PCPs) examined the frequency and treatment of attention deficit hyperactivity disorder (ADHD) in Swiss primary care, the differences between pediatricians and general practitioners (GPs) in handling ADHD, as well as the needs of PCPs regarding management of ADHD in practice. An average of 1 out of every 1000 consultations concerned suspected or confirmed ADHD, with pediatricians reporting 18x more consultations per 1000 than GPs. Male patients aged 7–12 represented the majority of consultations. Overall, 54% of pediatricians vs. 17% of GPs diagnosed ADHD themselves, and 88% of pediatricians vs. 40% of GPs treated the condition themselves. Both used medication in almost two-thirds of cases, with no gender-correlated differences observed in stimulant use. A lack of competence for diagnosing and treating ADHD was frequently reported, especially among GPs, and a corresponding need for better practical training and education was expressed. The self-reported lack of diagnostic and therapeutic expertise regarding ADHD among Swiss PCPs underscores the need for more training programs, better information on the disorder, and reliable easyto-use testing aids.

Key words: attention deficit/hyperactivity disorder; Switzerland; Sentinella; primary care; epidemiology



Introduction

The Swiss Sentinel Surveillance Network, "Sentinella", (https://www.sentinella.ch) is a cooperation venture between a volunteer group of about 170 physicians scattered across Switzerland, the Swiss Federal Office of Public Health (FOPH), and the Institutes of the universities of Lausanne (PMU, IUMSP, and IUMF), Bern (BIHAM), Basel (uniham-bb), Zurich (IHAM), and Geneva (UIGP). Initiated in 1986, its main purpose is to monitor common infectious diseases, facilitate research on primary health care, and serve as a tool for self-evaluation. A number of diseases able to be prevented through vaccination (e.g., influenza, mumps, and pertussis) are tracked yearly, and numerous others (e.g., Lyme borreliosis) in a sporadic fashion. Besides medical conditions, some healthcare-related events are monitored as well, e.g., vaccinations, HIV tests, emergency calls, and antibiotic prescriptions.

Surveying psychiatric conditions is not yet common in Sentinella. In 1986, suicide attempts were tracked for three years, depression for two years in 1988–1989 and 2008–2099, and eating disorder once in 2008.

In recent years, attention deficit (hyperactivity) disorder (ADHD) has become a growing public health concern in Western societies. The demand for stimulant medication has risen [1], as more and more parents have suspected the disorder in their children. The recognition of adult ADHD and the admission of methylphenidate for its treatment have boosted this effect. The prevalence of the disorder in children and adults is currently estimated at about 4% for each [2,3], which would amount to approximately 250,000 affected persons in Switzerland. In light of these figures, several psychiatrists have called for better standards of diagnosis and treatment.

At the same time, the diagnosis of ADHD and its treatment have engendered controversy. Voices from different segments of society – parents, doctors, and politicians – have expressed doubts regarding the reality of the disorder and the usefulness of stimulant medication. In extreme cases, ADHD has been referred to as a "Modediagnose" (a "fashionable diagnosis"), with pharmacological treatment considered to be a potentially dangerous way of imposing social conformity on misbehaving children [4]. More rigorous regulation of prescription practice was thus called for [5].

In response to such developments, the Sentinella program committee decided to incorporate ADHD into its 2012 survey. The stated aim was to "show to practitioners how prevalent the disorder is in primary care, how familiar it is, and how willing and able practitioners are to provide care for affected children, adolescents, and adults". More generally, the role of the primary care physician (PCP) in the management of ADHD was to be elucidated.

The survey was not intended to educate practitioners on the symptoms and diagnosis of ADHD, but to capture a snapshot of PCPs' current practices in dealing with suspected cases. The survey questions focused on frequency, diagnosis, and treatment. In the year 2014, a supplementary questionnaire was mailed out in order

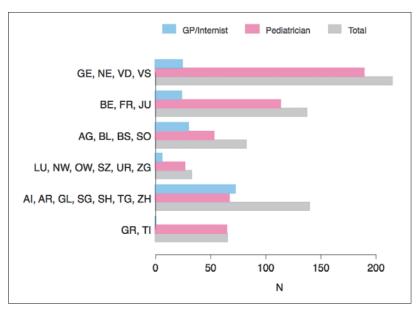


Figure 1: Distribution of ADHD-related cases by type of primary care physician and geographical region.

to collect additional data on physicians' perceived needs and competence in handling ADHD. The complete list of questions can be found in Appendix A, published with the online version of this article on www. sanp.ch.

In this report, we present findings from the 2012 Sentinella survey and the 2014 supplementary questionnaire on ADHD. Additionally, we render the original data publicly available to all interested parties wishing to conduct their own analyses (see Appendix B on www.sanp.ch).

Methods

Data collection

Sentinella physicians comprised general practitioners (GPs), internists, and pediatricians. They represented about 3% of all PCPs under the age of 65 years. Adult and child psychiatrists were not included in the sample. They were, however, part of the external specialists to whom some survey questions refer. Sentinella covers all of Switzerland and is divided into six administrative regions, according to cantons, as follows: 1) GE, NE, VD, VS; 2) BE, FR, JU; 3) AG, BL, BS, SO; 4) LU, NW, OW, SZ, UR, ZG; 5) AI, AR, GL, SG, SH, TG, ZH; 6) GR, IT. The questionnaires were distributed to participants by the FOPH, which was also responsible for collecting the data. Survey responses could be returned either by post or online.

The basic data unit on which participants reported was the consultation, defined as any contact between physician and patient, either in the practice or during a

house call. This included follow-up consultations for a single patient, which were to constitute separate data points. For the ADHD survey, physicians were asked to report any patient presenting with an established or suspected diagnosis, including those suspected by the physician himself or herself to have ADHD, and those being referred by the physician to external specialists for further evaluation. Patients with ADHD consulting for reasons unrelated to the disorder were not reported.

According to applicable Swiss law, ethics approval was not required for surveying volunteer physicians, given that full patient anonymity was guaranteed.

Ouestions

The main questions asked were:

- How frequent does (suspected) ADHD occur in primary care?
- How frequently is ADHD diagnosed by primary care physicians? How frequently do PCPs refer diagnosis and/or treatment to specialists?
- How competent do PCPs feel about diagnosing and treating the disorder? How exactly do they diagnose and treat it?
- Do pediatricians differ from other PCPs in their approach to diagnosis and treatment?
- What needs do PCPs have regarding management of ADHD patients?

The full set of questions can be found in the ADHD "module" of the 2012 survey, which is reproduced in Appendix A, along with the supplementary questionnaire.

Results

Frequency

In 2012, 75 physicians (37 GPs, 22 pediatricians, and 16 internists) reported a total of 675 ADHD-related consultations, 133 of which were first contacts. Over 90% of the data originated from physicians reporting for Sentinella at least 9 months of the year. The supplementary questionnaire was answered by 167 physicians, 65 of whom were participants of the 2012 survey. Responses to this questionnaire will be discussed in the section "The physician's view".

Each pediatrician reported an average of 23.5 ADHD-related consultations (range 1–67), which was roughly 8 times the number reported by GPs (mean 2.7, range 1–9) and internists (mean 3.8, range 1–13). The regional distribution of ADHD-related visits is shown in figure 1. On average, one out of 1000 consultations (0.1%) recorded by Sentinella was related to ADHD. Among

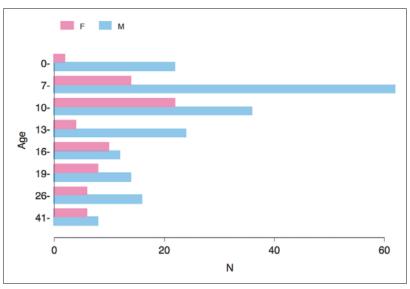


Figure 2: Age and gender distribution of ADHD-related first consultations.

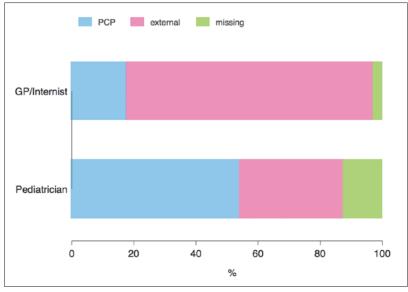


Figure 3: Differences between GPs and pediatricians in diagnosing patients with suspected ADHD. PCP = primary care physician. GP = general practitioner.

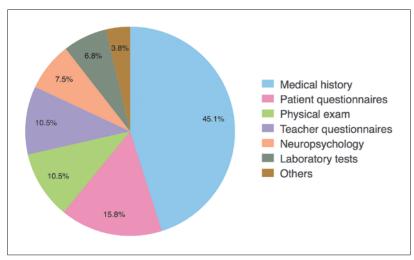


Figure 4: Diagnostic elements used by primary care physicians.

pediatricians, an average of 0.5% (5 per 1000, range: 0-46 per 1000) of consultations concerned ADHD, while among both GPs and internists, the figure was 0.03%, i.e., 18 times lower (0.3 per 1000, range: 0-6). The frequency of ADHD-related patient contacts also proved to vary by region. In particular, it was twice as high in the French-speaking part (1.7 per 1000) than in the remaining, mostly German-speaking part of Switzerland (0.8 per 1000). This figure, however, does not directly reflect the prevalence of ADHD patients. It is confounded by regional heterogeneity in the number of Sentinella physicians, in the proportion of GPs vs. pediatricians among them, and by the fact that many consultations constitute follow-up visits by the same individual. A closer approximation is attained via the mean number of first consultations (they must be for distinct patients) per GP and pediatrician, respectively, for each of the two parts of the country. Pediatricians in the French-speaking part had an average of 3.6±3.2 first consultations, compared to 3.8±3.2 in the rest of Switzerland. GPs in the French-speaking part on average had 1.1±1.1 first consultations, compared to 0.95±1.1 elsewhere. Note that these estimates may still be biased through a potential lack of representativeness in the sample of Sentinella physicians.

Male patients represented almost 80% of ADHD-related consultations (73% of first consultations). Among both genders, the majority of first contacts occurred at primary school age (7–12 years of age). The gender distribution by age category among first consultations is shown in figure 2.

Diagnosis

In 18% (121 out of 675) of consultations, a diagnosis had not been made yet, whereas either the patient or the physician suspected ADHD. Overall, 44% of such cases were diagnosed by the PCP, another 46% were diagnosed externally, and for the remaining 10%, data was either missing or no diagnostic evaluation had been performed.

Notable differences were observed in the diagnostic practice between GPs and pediatricians. Only 17% (6 out of 34) of patients with suspected ADHD consulting a GP were diagnosed by the GP himself or herself, whereas pediatricians diagnosed 54% (47 out of 87) of suspected cases themselves (patients remained undiagnosed or data is missing in 12% of consultations with pediatricians; see fig. 3).

Patients' medical histories constituted the most frequently named diagnostic element (45%), followed by questionnaires for patients (16%). Questionnaires for teachers and physical examinations were each indi-

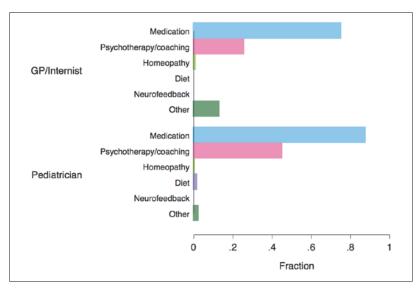


Figure 5: Forms of treatment administered by general practitioners vs. paediatricians.

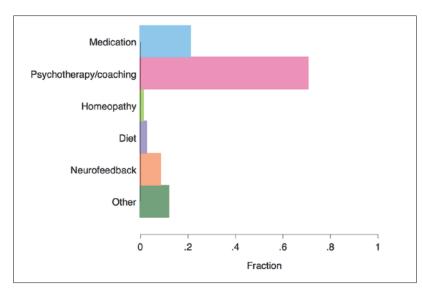


Figure 6: Forms of treatment administered by external care providers, as reported by general practitioners / internists and pediatricians. It should be noted that 66% of the data was missing.

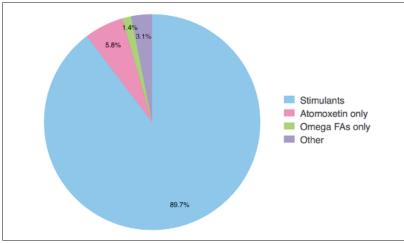


Figure 7: Medication used to treat ADHD. FA = fatty acid.

cated by 10% of participants. Another 7% of responses each concerned neuropsychological and lab tests (fig. 4). GPs more often based their diagnostic assessments exclusively on medical history (64% of consultations) than pediatricians, who used medical history in conjunction with patient and teacher questionnaires roughly equally often (in 25%, 22%, and 21% of cases, respectively).

In 554 consultations, the patient's diagnosis was already known at the time of the consultation, but had not yet been reported in the ongoing survey. Of these 554 diagnoses, 34% had been made by external specialists and 25% by PCPs. The remaining 41% of the data was missing. The PCP made the diagnosis either based on medical history alone (26%) or based on both history and psychological testing (74%).

Treatment

At most, two treatment options could be reported per consultation. PCPs reported the use of medication in 85% of consultations, and that of coaching and psychotherapy in 41%. Pediatricians relied more on medication (88%) and coaching/psychotherapy (45%) than GPs (75% and 26%, respectively). Homeopathy and dietary adjustments were recommended very rarely (see fig. 5). It should be noted that these percentages are based on the estimates given by PCPs on each consultation, and are relative to the total number of such reports given, which was 568 out of a possible 675. Furthermore, 16% of the data was missing.

External care providers relied much more on coaching/psychotherapy (71% of responses) than on medication (21%). Use of neurofeedback was rare (7%), with dietary adjustments and homeopathy even rarer (2% and 1%, respectively). In addition, 10% of cases were treated by other unspecified means (see fig. 6). It should be noted that these percentages are based on the estimates given by PCPs on each consultation, and are relative to the total number of such reports given, which was 230 out of a possible 675. Therefore, 66% of the data was missing.

When medication was used, it was almost always stimulants like methylphenidate (almost 90% of cases). Among the remaining choices, atomoxetine was most popular (7%), followed by omega-3 fatty acids and other compounds (see fig. 7).

GPs differed from pediatricians in their more frequent reports of "other", unspecified medications (13% vs. 7%). Use of stimulants at first consultation did not differ appreciably between male (32%) and female (39%) patients, but showed an age-related increase from no use below age 7 to 30%–50% at older ages.

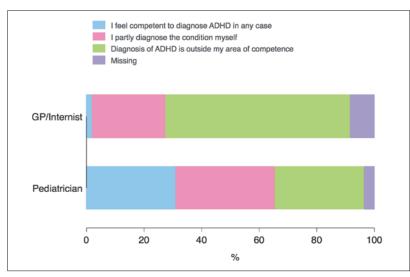


Figure 8: Perceived competence to diagnose ADHD among primary care physicians.

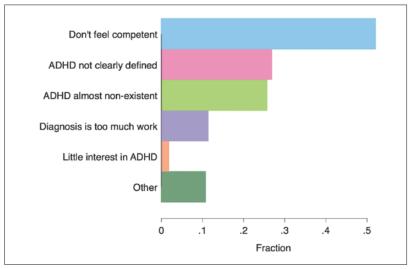


Figure 9: Reasons given by primary care physicians for diagnosing ADHD only rarely.

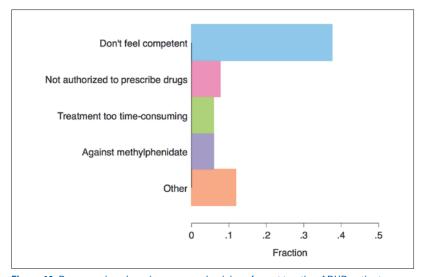


Figure 10: Reasons given by primary care physicians for not treating ADHD patients themselves.

The physician's view (supplementary questionnaire)

Overall, 31% of GPs and 96% of pediatricians (mean: 41%) were occasionally or frequently faced with the subject of ADHD in their practice. That said, only 7% of PCPs felt competent to diagnose ADHD in any case. About 28% made the diagnosis occasionally, while 61% did not feel competent enough and referred patients to external specialists. GPs generally felt less competent than pediatricians (65% vs. 38% did not feel competent, 26% vs. 42% felt somewhat competent, 2% vs. 38% felt fully competent; fig. 8).

When queried as to the reasons for diagnosing ADHD only rarely, participants primarily stated a lack of competence (52% of PCPs). Overall, 27% considered the disorder to be insufficiently well-defined, while another 26% found it to be almost non-existent in their own practice. The distribution of responses can be found in figure 9.

Roughly half of PCPs (88% of pediatricians, 40% of GPs) treated ADHD patients themselves. Physicians referring patients to external specialists most often did so because of a perceived lack of competence (38% of respondents). Other reasons given were a lack of permission to prescribe drugs (8%), treatment being too time-consuming (6%), and doubts about the usefulness of methylphenidate (6%) (fig. 10).

In light of the perceived lack of competence, 57% of physicians felt that the issue of ADHD in primary care deserved more attention. That said, a significant difference was observed between groups. Whereas the vast majority of pediatricians (88%) shared this view, this figure was only 52% for GPs. Leading specific needs for better management of ADHD included practical training (50% of physicians), better information on differential diagnosis, practice-oriented literature, and testing aids (fig. 11).

Discussion

The 2012 Sentinella survey provides a first look into current practices of ADHD management in Swiss primary care. The broad picture that emerges conforms with expectations, namely that pediatricians are much more commonly confronted with ADHD than GPs, they diagnose and treat such patients themselves significantly more often than GPs, and they feel more competent to do so than GPs. It likewise comes as no surprise that the diagnostic and therapeutic practices of pediatricians are somewhat more refined. In addition to medical and family history, they often employ questionnaires for diagnosis and more frequently supplement drug treatment with coaching and psy-

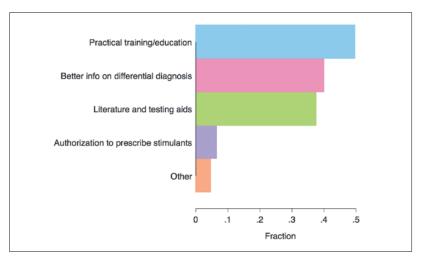


Figure 11: Specific needs of primary care physicians with regard to managing ADHD.

chotherapy. External caregivers, to whom GPs more often refer patients than pediatricians do, are even more strongly reliant upon coaching and psychotherapy, most likely because psychotherapy is frequently the very reason for referral to external specialists.

Most of the patients reported are in the age range of 7–12 years, reflecting the fact that ADHD, as manifested in primary care, still remains a problem primarily occurring in childhood. It seems plausible that children's symptoms may clash more severely with the rigid structure of school environments that they cannot avoid, whereas adults are relatively free in finding occupational niches that match their profile of strengths and weaknesses. Further, given the fact that adult ADHD has only recently been recognized as a valid disorder, a time lag will necessarily ensue before affected adults place their symptoms in the right context and seek help.

There is a strong preponderance of male patients, especially among children. Overall, three out of four consultations concern boys. This is comparable with published prevalence estimates [2].

PCPs from the French-speaking part of Switzerland report almost twice as many ADHD-related consultations (per 1000 overall consultations) than those from the rest of Switzerland. This raises the question as to whether ADHD prevalence might be higher in that part of the country. While there is tentative evidence of this from the C-SURF study in male conscripts [6], the mean number of first consultations per physician differs only little between the French-speaking and predominantly German-speaking regions and shows significant variation. Therefore, these results do not allow a conclusive interpretation.

Medication consists of psychostimulants in 9 out of 10 consultations. PCPs use medication four times as often

as external specialists. Most likely, this reflects common practice, wherein PCPs refer patients in need of psychotherapy or other non-pharmacological treatments to external specialists (e.g., psychologists, psychiatrists, etc.), while remaining in charge of patients' drug therapy.

Use of homeopathy and omega-3 fatty acids is negligible both in private practice and the external setting. There are no appreciable gender differences in the frequency of stimulant treatment, either in all or just the first consultations. This is in contrast to studies based on data from Swiss health insurers showing that in children and adolescents, methylphenidate is prescribed 2–4 times more often to boys than to girls [7]. This discrepancy is probably accounted for by differences in populations sampled by the different studies.

Stimulant treatment, however, increased with age, from no prescriptions under age 7 (where only off-label use is permitted) to relatively stable levels of 30–50% of first, and 50–70% of all consultations.

The most relevant insight gleaned from the supplementary questionnaire is the widespread lack of competence for diagnosing and treating ADHD reported by PCPs. Among GPs, 70% did not feel competent to diagnose the disorder, and 60% referred patients for external treatment, half of them for the aforementioned reason. Among pediatricians, one-third did not consider themselves competent to diagnose ADHD, and 12% referred patients for external treatment. Two aspects are of note here. Firstly, PCPs are not authorized to make a diagnosis of ADHD in adults and must refer patients to psychiatrists. Secondly, the admission of a lack of competence does not imply that PCPs do not act responsibly towards patients with ADHD.

The situation in other countries appears similar. GPs from the UK find detecting symptoms of mental illness in young people to be challenging [8], PCPs in the US feel uncomfortable diagnosing ADHD in adults [9], and US pediatricians are only moderately accurate in making correct ADHD diagnoses [10]. As a result, applied diagnostic criteria often differ from established research criteria [11]. Several studies note a lack of clear, practical guidelines and the need for increased education and training for PCPs [10, 11, 12]. There is particular demand for services targeting adults, especially adolescents transitioning into adulthood and therefore out of child and adolescent care [11, 13].

For this reason, PCPs both in Switzerland and elsewhere find themselves in the unenviable position of being confronted with a disorder they do not feel competent dealing with and which, at the same time, lies at the center of a controversy regarding the use of psy-

chostimulants in children. What should be done in such a situation?

Like their colleagues abroad, Sentinella physicians express a need for better practice-oriented training, better information on differential diagnosis, better literature, and better testing aids, and we likewise advocate such a demand. A similar call for strengthening physicians' continued education on diagnosis and treatment of ADHD was also made over 10 years ago in a pilot study conducted in the French-speaking part of Switzerland [14], which found almost twice as many ADHD-related consultations, compared to other parts of the country. Efforts are now underway to increase opportunities for training and education. For example, the Swiss Society of Pediatrics organized a first series of workshops on ADHD for pediatricians in 2014 and 2015, and the Swiss Society for ADHD followed suit with similar courses in the fall of 2015. The Swiss Society of Parents of Children with ADHD and of Adults with ADHD (ELPOS) also offers courses, although mostly geared towards parents and educators. In the long-term, it is hoped that diagnostic accuracy will be improved not only by increased clinical competence, but also by less subjective methods of diagnosis, e.g., via reproducible biomarkers [15].

Due to its structure, this survey exhibits notable limitations. Firstly, given that the basic unit of measurement was the consultation, inferences concerning patients are difficult to make. The same patient may occur in the records several times and cannot be identified. In some cases, we have restricted analysis to first consultations, as these must represent distinct patients, which significantly reduced sample size. These circumstances make it impossible to reliably assess, for instance, the question of ADHD prevalence or the proportion of patients prescribed stimulant medication. Secondly, it must be borne in mind that diagnoses were not established in this study. We are unaware how many of the patients actually met official ADHD criteria. Thirdly, given that the group in ques-

tion was self-selected, we are unaware to what extent the participating Sentinella physicians were representative of the population of Swiss GPs and pediatricians. Moreover, sample sizes varied considerably by region, making geographical comparisons unreliable. That said, the regional distribution of Sentinella physicians was similar to that of PCPs in general. Finally, comparability between PCPs and external caregivers proved limited given that patients seen by PCPs may differ systematically from those typically seen by external specialists (e.g., by constituting less severe cases). Data on such specialists (e.g., psychiatrists, child (neuro-) psychiatrists, or psychologists), who treat a large proportion of ADHD cases, should be collected in future studies.

In conclusion, the reported lack of diagnostic and therapeutic expertise in the field of ADHD reported by PCPs underlines the need for increased opportunities for practice-relevant training and education, as well as better testing aids. Such a call to action is explicitly supported by the surveyed physicians, and efforts to improve the situation are underway. The goal of comprehensive care would be further aided by programs to educate parents, teachers, policy-makers, the media, and the general public, in conjunction with more objective diagnostic tools.

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References

The full list of references can be found in the online version of this article on www.sanp.ch.

Appendix

The appendix can be found online on www.sanp.ch.

Correspondence:
Alex Gamma, Ph.D.
Department of Forensic
Psychiatry, Institute
of Forensic Medicine
University of Bern
Falkenplatz 16–18
CH-3012 Bern
alexander.gamma[at]fpd.

unibe.ch