

Experience of primary care services among early adolescents in England and association with health outcomes.

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ABSTRACT (250 words):

Purpose: To investigate adolescents' (11-15 years) experience of their general practitioner (GP), whether poor reported GP experience was associated with worse physical and mental health measures and whether poor previous GP experience was linked to lower utilisation of these services.

Methods: We used logistic regression to analyse data from the 2014 Health Behaviour in School-aged Children study. Four aspects of recent care experience were studied: feeling at ease, feeling treated with respect, satisfaction with doctor's explanation, and feeling able to discuss personal matters. Five dichotomised measures of health status were used: ever self-harmed; fair or poor self-reported health; frequent (at least weekly) low mood, sleeping problems or headaches.

Results: 4149/5335 students reported having visited their GP within the past year. Of these 91.8% felt treated with respect, 78.7% felt at ease, 85.7% were satisfied with explanation and 53.9% felt able to discuss personal matters. After adjusting for ethnicity, age, gender and family affluence score, poor experience on any indicator was strongly associated with increased risk of self-harm (Adjusted Odds Ratio (AOR) range 2.01–2.70 all $p < 0.001$); feeling low (1.53–2.11, all $p < 0.001$) and sleeping problems (AOR range 1.49–1.91, all $p \leq 0.001$). Poor experience on all indicators, except discussing personal matters, was associated with worse self-reported health.

Conclusions: Nearly half of this large, national study of adolescents did not feel able to discuss personal matters with their doctor. There was a consistent, strong association between reported lack of good GP experience and poor health measures.

Key words: Adolescent. GP. Patient experience. Primary care. Student. Health measures.

Implications and Contribution (50 words):

These findings show a strong association between poor healthcare experience and poor health. Adolescents with the greatest need report poorer experience of care, which may further exacerbate their health problems. Further research is needed to investigate the extent to which higher quality services can address these disparities and improve outcomes.

Main manuscript:

Adolescence is a key stage of the life course when lifelong health behaviours and attitudes to health care can be established.(1) Meeting the distinct healthcare needs of this age group is an important public health investment. (2) Unmet healthcare need in adolescence is linked to a range of increased health risks, and longitudinal data show that it is an independent predictor of poor mental and physical health outcomes as well as on-going unmet healthcare need in adulthood.(3)

Compared to many other countries, English adolescents have potentially good access to general practice services (English GPs are similar to family physicians, having responsibility for primary care needs of their patients), as the English National Health Service (NHS) offers comprehensive health services, free at the point of use. However, concerns have been raised about the quality of NHS care provided for adolescents and in particular about the responsiveness of services to young people's needs.(2) (4) Data from the UK and other high-income countries show that adolescents report poorer experience of inpatient services than other age groups and that young adults report poorer GP experiences than older adults.(5) One previous UK study showed that only 26% of 13-15 year olds felt able to talk to their GP about private things, and feeling unable to discuss private things was associated with lower consultation rates. (6) Despite government intentions since 2013 for children and young people to be included in all relevant patient experience surveys, the national patient surveys for GPs remains restricted to patients over 18 years of age. (7) (8) As a result, no national data have been reported on the GP experiences of patients under 18 years. However, in smaller studies, young people have reported dissatisfaction or avoidance of their GP due to concerns about

lack of confidentiality, feeling embarrassed or not being treated with respect by healthcare professionals. (9) (10)

National guidance, in particular the *You're Welcome* quality standards for young people friendly care, emphasise the importance of listening to the perspectives and experience of young people who use health services, and working in partnership with them to monitor and improve service quality. (2) (11)

Initiatives to train healthcare professionals in communication skills with young people have been shown to result in sustained improvement to patient satisfaction and professionals' confidence in their consultations with young people. (12) Small-scale projects have also suggested that high-quality services, which address the distinct healthcare needs of adolescents, can support young people to engage more actively with their own health and increases the likelihood of further attendances. (13) (14) However, little is known about whether poor GP experience in this age group is associated with worse health status or reduced healthcare utilisation.

Using data from the 2014 Health Behaviour in School-Aged Children (HBSC) survey (England), we wished to investigate:

1. The experience of GP care in a large, national sample of early/mid adolescents.
2. Whether poor reported GP experience was associated with worse physical and mental health measures.
3. Whether poor previous GP experience was linked to lower utilisation of GP services.

Methods

Participants and details of HBSC England methodology

The World Health Organization (WHO) Health Behaviour in School-aged Children (HBSC) study is a cross-national survey-based study addressing the health and wellbeing, health behaviours and social determinants of young people aged 11, 13 and 15 years old. (15) Data is collected through self-completed surveys administered during class time. The study is conducted every four years across Europe and North America following an internationally approved protocol. (16)

The sample for the present paper is comprised of English students who completed the 2014 HBSC survey. The survey includes international mandatory items and optional country-only questions, allowing for flexibility for inclusion of issues of national importance. Both the self-harm and service use questions were national questions. A random sample of all secondary schools in England, both state and independent, stratified by region and school type was drawn. The original sample consisted of 100 schools of which 48 schools were recruited resulting in 5335 students from 261 classes.. There was a fairly even gender split (51.5% male), and each of the three age groups were well represented (39.8% 11 year olds, 30.0% 13 year olds and 30.2% 15 year olds). The majority of the sample was White British (76.8%). The response rate at the student level was 92%. For full details of methodology see Brooks et al. (17) Ethical approval was granted from the University of Hertfordshire Ethics Committee for Health and Human Sciences (HSK/SF/UH/00007).

Variables

Health measures included five survey items. Students were asked how often in the last 6 months they had experienced any of: a) headaches, b) feeling low and c) sleeping difficulties. Response options varied from “about every day” to “rarely”, and were aggregated to create a dichotomous variable. Students also reported general self-rated health (excellent/good/fair/poor), with the upper two and lower two response options combined to form a binary variable. Lastly, 15 year olds were asked if they had ever self-harmed (yes/no). As outlined in appendix 1, poor health measure responses (defined as symptoms occurring weekly or more frequently, having ever self harmed, or fair/poor self reported health) were coded as “1” with all other responses coded as “0”.

GP experience was measured through five items. The first item assessed whether the student had visited their GP within the last year (yes/no). The remaining items focused on their experience of their last consultation. Being able to talk to the GP about personal things was also a binary variable (yes/no). Feeling at ease with, and feeling respected by the GP as well as GP providing good explanations were rated on a five point Likert scale from strongly agree through to strongly disagree. As outlined in appendix 1, the responses were aggregated to create a dichotomous variable, with positive experiences coded as “1” and negative or neutral experiences coded as “0”.. The patient

experience measures were adapted from questions that had been used in previous surveys, and are consistent with the wider literature on measuring the quality of health care for adolescents'. (6,18,19)

Demographics including age, gender, ethnicity and social economic status (SES) were included. SES was measured via the family affluence scale (FAS), a proxy measure of SES, based on a set of questions relating to material wealth in the family home. Consistent with recent HBSC work, the raw FAS was converted into three tertiles, as outlined in appendix 1, categorising respondents into the bottom 20%, middle 60% and top 20%. (15)

All statistical analyses were conducted using SPSS. Where the response rates were compared between cohorts in order to assess statistical significant differences, this was done using two-tailed Fisher's exact testing.

Results

Confirming existing research, we found that adolescents reported being fairly regular users of general practice. Of 5177 students who answered the question, 4149 (80%) were found to have visited their GP in the past year. The 158 participants who did not answer the question were excluded from all subsequent analyses.

Table 1 shows that males were less likely to have visited their GP and that younger adolescents were more likely (81.5%) to have seen their GP compared with their older peers (78.5%).

There was no statistical difference between attendance rates across different ethnic groups. However there was a statistically significant difference in attendance rates between young people who were from the least affluent families (77.2%) compared with those from the most affluent (84.1%).

As Table 2 shows, students who had visited their GP within the past year were more likely to report frequent headaches (29.9%) compared with those who had not (24.4%). GP attendance was not related to any significant difference in the other four health measures. Of young people who had

visited their GP, 46% had poor self-reported health, 26.4% reported frequently feeling low, 33.9% reported experiencing regular sleeping difficulties and 22.5% reported having ever self-harmed.

In relation to our first research aim, to explore the GP experience in this age group, results were positive. Table 2 shows that students who visited their GP within the past year were more likely to report a good experience with their GP. Specifically, 91.8% felt treated with respect 78.7% felt at ease with their GP, 85.7% were satisfied with their GP's explanation and 53.9% of those who attended felt able to talk to their GP about personal things.

Following this, we exclusively analysed data of students who had visited their GP in the past year. Table 3 shows that of these respondents, boys were more likely to report feeling at ease and being satisfied with the GP's explanation than girls. Adolescents in the youngest and middle age groups were also more likely to respond positively to their GP's explanation and be at ease with their GP than their older peers.

Between different ethnic groups, there were few differences in the experiences of those who attended. Adolescents of "other" ethnicity were significantly less likely to be satisfied with their GP, adolescents of mixed ethnicity were significantly less likely to be able to talk to their GP about personal matters whilst, adolescents of Black ethnicity were less likely to feel at ease with their GP..

Adolescents from families of lower affluence reported poorer experiences of their GP than adolescents from more affluent families. These young people were less likely to feel respected, to feel at ease, or feel able to discuss personal matters to their GP than those from families of moderate affluence. There was no significant difference in GP experience between the most affluent and middle affluence groups.

Our second research aim related to whether a lack of good reported GP experience was associated with worse physical and mental health measures. As Figure 1 illustrates, students who did not report

good GP experiences were more likely to report poor health measures. This was consistent across all health and experience measures.

Of those who did not feel able to talk to their GP, 32% had self-harmed at least once before, compared with 23% of those who did feel able to talk. Similarly, 40% of those who did not feel at ease with their GP reported feeling low at least weekly, compared with 23% who did feel at ease. Sleeping problems were reported by 48% of young people who did not feel satisfied with their GP's explanation compared with only 32% of those who were satisfied (all $p < 0.0001$).

These findings were consistent when adjusted for ethnicity, age, gender and family affluence score through a series of binary logistic regressions, with results outlined in Table 4. Adolescents who did not feel at ease with their GP were more likely to report self-harm (adjusted odds ratio [AOR] 2.68, 95% CI 1.93–3.71; fair or poor health 1.87, 1.50–2.34; low mood 2.02, 1.68–2.43) and sleeping problems (1.91, 1.61–2.26, all $p < 0.001$). These adolescents were also more likely to report frequent headaches (1.27, 1.06–1.51, significance 0.01). All GP indicators were strongly associated with self-harm (AOR range 2.01–2.70 all $p < 0.001$); feeling low (1.53–2.11, all $p < 0.001$) and sleeping problems (AOR range 1.49–1.91, all $p < 0.001$). Most measures of GP experience were strongly associated with self-reported health (AOR range 1.57–2.17, all $p < 0.001$) with the exception of feeling able to talk to the GP about personal issues (AOR 1.15, 0.94–1.40 $p = 0.2$). Additionally this measure of GP experience had no significant association with headache frequency.

Our third and final research aim was to explore the relationship between visiting a GP and having had a previous poor GP experience. Table 2 shows that students who hadn't visited their GP within the past year were more likely to report a poor or neutral previous GP experience than those who had visited. Of those who hadn't visited, 77.6% felt treated with respect (compared with 91.8% of those who had visited in the last year), 59.4% felt at ease with their GP (compared with 78.7% who had visited), 70.3% were satisfied with their GP's explanation (compared with 85.7% who had visited),

whilst 40.7% felt able to talk to their GP about personal matters (compared with 53.9% who had visited).

Discussion

In this large, national study of young people aged 11-15 in England, the majority of young people reported that they felt respected by their GP and were satisfied with their explanations. Overall, the GP experience amongst adolescents was positive. However, a significant minority did not feel at ease with their GP and only around half felt able to talk their GP about personal issues.

Males were less likely to have attended their GP, as were older students. Previous surveys suggest that young women's presentation rates increase in early adolescence, most notably from age 14/15.

(20,21) From the presented data it is not possible to confirm or refute whether this effect was present in the HBSC sample and whether the reduced attendance rate in older students was caused by primarily reduced male attendance.

There was a consistent, strong association between reported poor health status and lack of good GP experience. As well as showing a worrying inequity in some aspects of perceived service quality (i.e. the young people with the greatest health needs report a disproportionately poor GP experience) this suggests that opportunities for early intervention may be missed. For example, the association is particularly strong for mental health measures (deliberate self-harm and low mood) where early intervention from a trusted, high-quality service can lead to improvements in long-term health outcomes. (22) Increasing evidence of unmet need for mental health services among young people and the importance of early intervention, has informed current US policies to promote mental health screening and if adopted internationally may help address the needs of other vulnerable adolescents. (23) (24)

Young people who reported a poorer GP experience were less likely to have seen their GP within the last year, despite reporting more health problems. These findings should be interpreted with caution, given the potential for recall bias over such a prolonged period, but they may suggest poor experience

of care may put young people off seeing their GP, resulting in them not receiving the care they need. This finding is consistent with previous literature showing that young people who report a positive experience of healthcare services are more likely to attend again in the future. (14)

The role of poor GP experience in contributing to poor health measures and lower health care utilisation cannot be assessed in cross-sectional data. However these findings are consistent with extensive qualitative data that poor communication skills, perceived lack of respect or judgemental attitudes among healthcare providers may be particularly likely to lead to disengagement and poor health outcomes among adolescent patients.(9,10,25) Conversely, being able to talk to a trusted doctor may be particularly important for many of the most vulnerable young people, and may have an important protective effect on future health outcomes. (26)

Constructive and supportive relationships with adults - both teachers and parents - have been strongly and independently associated with contributing a protective health effect for young people. (27–29)

The findings presented here suggest that GPs could also constitute an important additional element in the set of constructive adult relationships around the adolescent. The findings also corroborates previous work suggesting that particular skills are required to work with young people, including emphasise on confidentiality, enabling young people to feel their concerns are heard and seeing young people without a parent. (30)

Furthermore, while ecological analysis has often considered the role of family and school as protective domains, more recently a sense of belonging to local neighbourhood or community has been demonstrated to constitute a significant protective health asset. (31) How primary health care services might function as a component of a positive community effect has been less thoroughly explored and warrants further examination.

Strengths and limitations

This was a large, national study. As a school-based survey, it provides representative information on the general population, unlike patient experience surveys, which are only sent to those who have had

recent contact with health services. The response rate was very high (over 90%) in contrast to some school-based surveys in other countries which report much lower rates of parental agreement to participate. (32) Another strength is that the questions include a range of important health complaints among this age group and key aspects of GP consultations that have been highlighted in previous literature. (33) However, other data which have been previously studied and would have been of interest were not included. These include the reason for seeing their GP, and whether or not they were seen alone.

Although these findings are particularly relevant to policy makers and practitioners in the UK, they may also be of interest in other countries such as the US, where much research into health outcomes and healthcare experience focuses on inequalities in access to care and/or concerns about the quality of care provided to uninsured/underinsured adolescents.

In common with all cross-sectional studies, these data do not allow us to investigate causality. There is likely to be a bi-directional relationship between healthcare experience and health measures, with poor healthcare experience contributing to poor health measures in some cases, and persisting health problems leading to dissatisfaction with their doctor in others. Additionally the methods of sample selection and the wording of questions in this survey were different from those used in adult questionnaires, so direct comparisons cannot be made between different age groups. This limitation can only be overcome through inclusion of children and young people in routine national surveys of healthcare experience, as recommended by an expert group commissioned by the English Government in 2012. (4) As this was a school-based survey, another limitation is that it may not reach the most vulnerable young people who may not have been attending school the day the survey was conducted.

Lastly, there is potential for bias when comparing adolescents' recent memories of care (within the last year) with older memories. It is possible that negative experiences will be remembered more clearly over time. This limitation is compounded by the fact that only one informant, the young person, influenced the variables.

Conclusions and implications for policy and practice

In this large, national study of adolescents aged 11-15 years, there was a consistent, strong association between reported poor or neutral GP experience and poor health measures. Nearly half of the young people felt inhibited in talking to their GP about personal issues. Rates of self-reported low mood and self-harm were much higher than might have been anticipated from other surveys. (34) Overall, the results emphasize the importance of raising awareness of adolescent health in general practice.

The relative lack of international literature in this area could usefully be addressed by including these or similar questions in all country surveys in the next round of the HBSC survey. Both health measures and the number of doctor visits among adolescents are known to vary considerably between countries, but little comparative data on healthcare access and experience is available. (35,36) Such cross-country studies of adult healthcare experience have been important in highlighting relative areas of strength and weakness of different country health systems. (5)

Existing literature and observational data suggest that high-quality primary care services which meet adolescents' distinct needs may result in significant improvements in adolescents' experience of primary care, but these pockets of good practice are unusual. (37) If prevention and early intervention are to be taken seriously, policy makers and commissioners need to raise the bar in primary care across the board. This may imply a renewed focus on ways of incentivising primary care to invest in adolescent health.

Changes in practice will require a change in the culture of healthcare delivery for adolescents. Two key aspects of this are leadership and investment in training. Despite good evidence that communication skills training can improve the quality of consultations with young people, as well as evidence that physician and nurse postgraduate training in youth health can improve students' mental health outcomes paediatric and adolescent health training are currently not statutory for British GPs.(12) (38) Another area for improvement is appropriate recognition of adolescent health in national quality frameworks. For example, the quality and outcomes framework that underpins general practice in England has never included any clinical indicators linked to young people, with the exception being asthma. Although they only offer good practice guidelines, rather than compulsory

standards, schemes such as the English '*You're Welcome*' quality criteria for provision of healthcare to adolescents are an important way forward.

While recent declines in emotional well-being among the UK adolescent population have been reported, the majority of interventions tend to be focused on school based programmes, especially social learning programmes. (15) These data suggest that improving the accessibility and quality of primary care may also have a key role to play in improving mental and physical health outcomes for young people in the UK and internationally.

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