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The accuracy of parent/carer proxy-reporting of caries experience in children and association with socioeconomic circumstances: a cross-sectional data linkage study

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Objectives: To compare parent/carer proxy-reported dental caries experience of their 5-year-old child with epidemiological survey clinician examination of caries experience in the same children. To determine any differences in the accuracy by area-based socioeconomic group. ***Methods***: A cross-sectional data linkage study linked data from the Growing Up in Scotland (GUS) study and the National Dental Inspection Programme (NDIP) school epidemiology survey. Parent/carer proxy-reported caries experience was compared with clinician-measured caries experience on n=3008 children, and data were stratified by home-residential area-based socioeconomic deprivation levels (Scottish Index of Multiple Deprivation (SIMD)). Sensitivity, specificity, positive predictive value (PPV) and negative predictive value (NPV) were calculated overall and stratified by SIMD. ***Results***: Overall, parent/carer proxy-reporting had low sensitivity (42.3% 95%CI: 39.0, 45.7) that decreased with decreasing deprivation (SIMD-1(most deprived): 49.4% to SIMD-5 (least deprived): 37.2%). Specificity remained consistently high overall and across area-based socioeconomic deprivation levels (overall=96.2%, 95%CI: 95.3, 97.0; SIMD-1: 94.4% SIMD-5: 97.8%). In children whose parents/carers reported them to have caries experience (GUS) a high percentage were found to have caries experience (NDIP) (PPV=81.8%, 95%CI: 78.2, 84.9). ***Conclusion***: Parent/carer proxy-reporting of caries experience in 5-year-old children had very low sensitivity and was lowest in children from the least deprived areas. In contrast, parents/carers who reported their child had caries experience did so reasonably accurately. This study concludes that proxy reporting caries experience is not sufficiently sensitive to replace clinician examination in assessing dental caries experience in surveys of child populations and highlights the importance of data linkage to routine datasets.

Keywords*: epidemiology, socioeconomic factors, dental caries, self-report, child health, medical record linkage*

Introduction

Dental caries affects 514 million children globally (World Health Organisation, 2022) and in higher income countries, almost a third of these children have untreated decay with large and persistent inequalities (Conway *et al.*, 2014; Peres *et al.*, 2019). In Scotland, caries experience in children has improved over the past 20 years although inequalities remain stubborn. Annual data on caries experience in 5- and 11-year-olds in Scotland are obtained from the National Dental Inspection Programme (NDIP), a school-based population-wide oral health survey that covers almost 90% of all children in these age groups (Macpherson *et al.*, 2019). Caries experience is recorded by teams of trained dentists using a standardised protocol and the data are used to assess individual child treatment need and local area service delivery and for epidemiological purposes. The need for these large and costly epidemiological surveys has been debated previously (Silman *et al.*, 2018) with self/proxy-reporting possibly a more efficient way to collect information on large populations (Jones *et al.*, 2013).

Parent/carer proxy reporting, whereby the parent/carer reports health or behaviours on behalf of the child, necessitates them to understand behaviours, feelings, and experiences of the child, as well as being able to communicate this accurately. This form of proxy reporting can be beneficial due to the varying levels of a child's ability to report on their own health (Mpundu-Kaambwa *et al.*, 2021; Paul *et al.*, 2023). Moreover, proxy-reporting can capture information that is not easily accessible through clinical examinations alone, such as pain perception and treatment preference. It is also less invasive and more cost-effective than many other methods. Despite these possible advantages, proxy-reporting of child oral health may exhibit limitations. Errors are an inherent part of scientific research and are more apparent in studies that involve more subjectivity, such as proxy reporting. Validity concerns may arise in these findings due to a plethora of possible errors, mainly social desirability, and memory concerns (Upton *et al.*, 2008; Mack *et al.*, 2020). This all needs to be considered before using proxy-reporting as a means of collecting information.

A secondary analysis comparing maternal proxy-reporting of child caries experience against clinician assessed caries experience was carried out across 774 local government areas in Nigeria using 1549 children under the age of 6 years (Folayan *et al.*, 2020). This study used the decayed-missing-filled teeth (dmft) index (Pine *et al.*, 1997) to define dental caries experience and found that parents under-reported the prevalence in their children. They also explored the socioeconomic impact of mother's age, income, educational status and ability to act independently. Higher maternal income and ability

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to make independent decisions were associated with more accurate proxy-reports. Both factors are believed to be key to high utilisation of dental services in Nigeria. Conversely, greater education saw a decrease in the accuracy of the reporting, the reason for which was not explored in the paper. Studies comparing the accuracy of parent reporting to the child self-report equivalent are more commonplace, usually for subjective outcomes such as health related quality of life, such as Ooi et al. (2020) with regards to obesity and Blake et al. (2020) with sickle cell disease. Mack et al. (2020) explored the level of agreement between symptoms and functioning of children receiving cancer treatment. All three of these papers found that parents couldn't consistently agree with the child self-report and advocated using child's own report wherever possible. A final paper explored correlation between child and parent ratings and diagnostic accuracy of the parental rating in a cross-sectional study of 140 children in Cologne aged 7–17 years and was assessed with the 19-item Child Oral Health Impact Profile (COHIP) (Reissmann *et al.*, 2017; Broder *et al.*, 2012; Sierwald *et al.*, 2016). They too found minimal concordance and deemed the diagnostic precision of the parent ratings inadequate.

Whilst proxy-reported caries experience offers potential time and cost advantages over clinician measured experience, a direct comparison between the two measures in young children is necessary. The aim of this study was to compare the accuracy of parent/carer proxy-report of child caries experience with clinician measured caries experience and assess whether accuracy differed by area-based socioeconomic deprivation levels.

Methods

This was a data linkage, cross-sectional study comparing proxy-report with clinician examination measured caries experience among children in the Growing Up in Scotland (GUS) cohort study who were born in 2004/05 *and* who underwent a basic dental inspection in Primary 1 (aged ~ 5 years) between 2009 and 2011 as part of the National Dental Inspection Programme in Scotland.

Growing Up in Scotland (GUS) is a cohort study tracking all aspects of a child's life from birth onwards in two separate nationally representative birth cohorts and a child cohort. For this study, data were analysed from the first birth cohort of children born between 01/06/2004 – 31/05/2005 (n = 3833) at ~ 5 years old in the 5th sweep of data collection (Bradshaw *et al.*, 2011). The National Dental Inspection Programme P1 was an annual survey of caries experience in children in their Primary 1 school year (approximately 5 years old) attending local authority and some public schools. The dental inspection involved a simple assessment of the mouth and teeth of each child by trained and standardized primary care dental teams within primary schools. For this study GUS records were linked to the NDIP in school years 2009/10 and 2010/11.

Data Linkage used the Electronic Data Research and Innovation Service (eDRIS), with a strict disclosure protocol. The data were linked at an individual level to Scotland's list of unique patient identifiers, the Community Health Index (CHI) number, using probabilistic matching on key variables using date of birth, sex, and postcode. The linkage agent pseudonymises study specific identifiers allowing individuals to be linked across both data sets stored within the National Safe Haven. The NDIP dataset and the GUS dataset have both been subject to data cleaning and quality assurance using standard operating procedures (SOPS).

GUS caries experience was a derived binary variable coded as "1" if the child's parents/carers reported that their child had tooth fillings, had a decayed tooth extracted, or had some or a lot of decay, and "0" otherwise. The questions used for this can be found in the GUS data documentation (Bradshaw *et al*., 2011).

NDIP Caries Experience (yes/no) is illustrated in Table 1 by any category defined in section A or the first, third or fourth categories in section B (Macpherson *et al*., 2020). A secondary measure of Gross Caries was considered to allow for the fact parents/carers may identify gross caries more readily. This is only the most extreme cases and is only defined as yes for anything defined in section A of Table 1.

Table 1. National Dental Inspection Programme Examination Criteria.

NDIP Examination (Up to 2014/2015)	
Letter	
A	Abscess or infection Gross Caries Obvious caries permanent tooth
B	Obvious caries primary tooth Possibly carious permanent tooth Missing Primary molar Evidence of restorations Poor oral hygiene
C	No obvious caries experience

The Scottish Index of Multiple Deprivation (SIMD) 2009 was used as an area-based deprivation measure (Scottish Government, 2009). It is based on 38 indicators in seven individual domains of current income, employment, housing, health, education, skills and training, geographic access to services and crime. SIMD is calculated at data zone level, enabling small pockets of deprivation to be identified. The data zones are ranked from most deprived (1) to least deprived (6,976) on the overall SIMD index. The ranked data zones were then categorized into fifths.

Caries experience (and gross caries) (as measured by NDIP) was cross tabulated with proxy-reported caries experience (as measured in GUS). Sensitivity, specificity, positive predictive value, and negative predictive value were calculated (Altman and Bland, 1994; Trevethan, 2017).

The study received ethical approval (College of MVLS, University of Glasgow) and approval from the Public Benefit and Privacy Panel - Health and Social Care (PBPP- Public Health Scotland) and the Statistics- PBPP (Scottish Government) (reference number: 200170146). Reporting used the STROBE guidelines (von Elm *et al*., 2008).

Results

There were 3833 children in the GUS Birth Cohort 1 in the school year 2009/10 (Sweep 5 – Aged 4 – 6 years) of which 3422 (89.3%) are present in the National Safe Haven. Those missing (n=411) did not give consent for their survey data to be linked to routine administrative data.

There were 51,074 Primary 1 children who had a NDIP record in the same timeframe. Of the 3422 children who had proxy reported caries experience in GUS, 3214 (93.9%) had a corresponding NDIP record. Those not in the NDIP database are likely to have attended the schools who did not participate in the dental inspection (approximately 5%). Four children present in GUS data set had missing data for all three proxy-reported questions. Of these 3210 children, 202 attended NDIP participating schools but did not receive a dental inspection on for various reasons (child was absent or refused) leaving 3008 children with both measures of caries experience. Of the 3008 children included 50.5% were male and 49.5% female. In this group, 17.5% lived in the 20% most deprived areas of Scotland (SIMD1), 18.0% in SIMD2, 19.5% in SIMD3, 22.8% in SIMD4 and 22.2% in the 20% least deprived areas (SIMD5).

The comparison of the proxy-reported caries experience from the GUS survey with the clinician measure in NDIP and gross caries from the 3008 children is presented in Table 2.

Based on the NDIP, 28.6% of children had caries experience, whereas only 14.8% had caries experience based on the parent/carer proxy-report. Gross caries was reported in 7.2% of children.

For those with caries experience in the NDIP only 42.3% had proxy-reported caries experience (sensitivity) in GUS. In contrast specificity was high with 96.2% of those with no caries experience (NDIP) reporting correctly via proxy report in GUS. The sensitivity did improve slightly for gross caries (47.5%), while the specificity decreased to 87.7% as children without gross caries could still report to having caries (GUS caries experience v NDIP gross caries only). In parents/carers who reported their child to have caries experience (GUS), almost 82% had clinician verified caries experience (PPV); with the no caries equivalent (NPV) similar at almost 81%. The overall accuracy of the reporting is 80.8%.

In table 3, these results are then partitioned by area-based deprivation fifths (SIMD) to explore the effects of socioeconomic circumstances and their Sensitivity, Specificity, PPV, NPV, Overall Accuracy and Caries Prevalence.

Sensitivity was lowest in children living in the top 40% least socioeconomically deprived areas of Scotland and highest in children living in the 20% most deprived areas. In general sensitivity decreased as levels of deprivation decreased. Specificity remained consistently high; always above 94%. The PPV followed a similar pattern as the sensitivity, with the lowest PPV among children

Table 2. Comparison of Caries Experience/Gross Caries (NDIP) with GUS proxy-report.

		NDIP[1]				
		No Caries Experience (%)	*Caries Experience (%)*	*No Gross Caries (%)*	*Gross Caries (%)*	*Total*
GUS[2]	No Caries experience	2067 (96.22)	496 (57.67)	2449 (87.71)	114 (52.53)	2563
	Caries experience	81 (3.78)	364 (42.33)	342 (12.29)	103 (47.47)	445
	Total	2148	860	2791	217	3008

[1] - National Dental Inspection
[2] - Growing up in Scotland

Table 3. Sensitivity, Specificity, Positive Predictive Value, Negative Predictive Value, Overall Accuracy and Caries Prevalence for Caries Experience (NDIP) vs GUS proxy-report partitioned by SIMD fifths.

SIMD	*Sensitivity (95% CI)*	*Specificity (95% CI)*	*PPV[1] (95% CI)*	*NPV[2] (95% CI)*	*Ovr Accuracy (95% CI)*	*Prevalence (95% CI)*
ALL	42.33 (39.00, 45.71)	96.23 (95.33, 96.99)	81.80 (78.16, 84.94)	80.65 (79.73, 81.53)	80.82 (79.36, 82.21)	28.59 (26.98, 30.24)
1-most deprived	49.37 (42.87, 55.89)	94.43 (91.10, 96.78)	88.06 (81.83, 92.35)	69.13 (66.33, 71.80)	73.95 (69.98, 77.66)	45.44 (41.12, 49.80)
2	43.01 (35.79, 50.46)	95.77 (93.13, 97.62)	84.21 (75.98, 89.99)	76.23 (73.86, 78.45)	77.63 (73.88, 81.08)	34.38 (30.38, 38.55)
3	42.14 (34.36, 50.21)	96.96 (94.86, 98.37)	83.75 (74.54, 90.07)	81.85 (79.78, 83.76)	82.11 (78.77, 85.13)	27.09 (23.53, 30.88)
4	34.53 (26.68, 43.06)	95.42 (93.31, 97.02)	65.75 (55.14, 75.00)	85.13 (83.52, 86.61)	83.07 (80.04, 85.50)	20.29 (17.34, 23.50)
5- least deprived	37.23 (29.13, 45.89)	97.75 (96.10, 98.83)	80.95 (69.99, 88.57)	85.83 (84.18, 87.34)	85.37 (82.47, 87.96)	20.45 (17.15, 23.70)

[1] - Positive Predictive Value
[2] - Negative Predictive Value

from the 40% least deprived areas and the highest among children from the most deprived areas. There was a notable PPV outlier at SIMD 4; more than 15% lower than any other SIMD fifth. NPV and overall accuracy both increased as deprivation decreased, approximately 16% and 12% respectively. These two statistics, however, would be affected by the marked decrease in prevalence from SIMD1 to SIMD5. The GUS reported prevalence was 25.48%, 17.56%, 13.63%, 10.66% and 9.40% from SIMD 1 to SIMD 5 respectively. This resulted in the absolute prevalence difference decreasing from 19.96% to 11.05% as deprivation decreased when comparing NDIP against GUS, however, the reported prevalence ratio increased from 1.78 to 2.18.

Discussion

This study compared the proxy-reporting of caries experience against a standardised clinician examination on a cohort of children approximately 5-years-old. Parental/carer proxy-reported caries experience identified in the NDIP had very low sensitivity (<50%) even when only considering gross caries experience, which should be visibly obvious. The sensitivity decreased further in people from less deprived areas. In contrast, specificity remained high across all SIMD fifths. The positive predictive value (PPV) was also high, indicating that parents'/carers' reports of decay, fillings or missing teeth in their child were reasonably accurate, however it also followed a similar socioeconomic pattern as sensitivity. Another key finding was the high net reporting error with almost double the caries experience prevalence in NDIP to GUS, this ratio increased as deprivation increased following a similar socioeconomic pattern to sensitivity and PPV.

The findings of low sensitivity of parental/carer report of child caries experience aligns with previous research (Folayan *et al*., 2020) and indicates that parental/carer reporting may not be suitable as a valid tool to measure child caries experience.

The impact of socioeconomic factors on reporting accuracy was seen in this study through the lower sensitivity in the least deprived SIMD fifths (SIMD1 = 49.37% vs SIMD5 = 37.23%), however which and how many aspects of deprivation impacted on carers' diagnostic sensitivity is unclear. Folayan et al. (2020) concluded that sensitivity increased with higher maternal income but decreased with higher maternal education. The same authors compared various stages of dentition, finding a much lower prevalence of caries in their sample (4.50% vs. 28.59%). This difference could be attributed to their inclusion of a wide age range of children under 6 (n = 1155), whereas the current study focused only on children approximately 5 years old (n = 3008). Additionally, Folayan and colleagues' data were collected from a single city in Nigeria, whereas the prevalence of caries varies drastically across the country (between 4% and 40%) (Braimoh, Umanah and Ilochonwu, 2014). It is important to consider the cultural, social, and environmental differences between the two countries where the studies were conducted, when comparing the findings; however, Folayan et al's findings could partially explain the underlying reasons for the decrease in sensitivity with increasing socio-economic status.

Looker (1989) asserted that education is a pivotal socioeconomic indicator in proxy reporting, suggesting its potential significance as a key driver in the socioeconomic patterns observed in the current study. These findings were partly reinforced by Imes et al (2021); however, due to the more ambiguous nature of their oral health question and their sample differing notably from this study; low-income, high-risk and multi-ethnic the findings may not be entirely transferable. This study also introduces ethnicity as a key factor in the differences in reporting; while there are other studies that report an improvement in health reporting from minority ethnic groups (Bombak and Bruce, 2012; Mindell *et al.*, 2014). The potential confounding of ethnicity impact on the current study is likely to be minimised due to the low proportion of Black, Asian and minority ethnic groups present in the cohort (approximately 3%); however, the complex relationships between ethnicity, socioeconomic position, and health in Scotland should be noted (Walsh *et al.*, 2019). The effect of parental education levels on proxy-reporting has also been explored in a wider health setting such as obesity (Cullinan and Cawley, 2017).

The accuracy disparities across SIMD may be attributed to social desirability bias, which includes a fear of judgment, social stigma, and the desire to present oneself positively. Specific to education; higher educated individuals may be more susceptible to social desirability bias due to their heightened awareness of medical recommendations, public health messaging, and the health implications associated with certain conditions or behaviours (Cullinan and Cawley, 2017). These are all applicable to dental caries (Imes *et al.*, 2021) and could cause it to be underreported (Pitiphat *et al.*, 2002).

The current study underscores the limitations of solely proxy-reporting for recording dental caries experience prevalence and suggests an influence of socioeconomic factors on subjective reporting. These findings provide valuable insight suggesting the necessity to continue with large population wide epidemiological surveys (such as the National Dental Inspection Programme in Scotland) to report on outcomes such as dental caries. The current study is believed to be the first in a high-income country that has directly compared parental/carer proxy-reporting accuracy against a standardised clinician reporting of dental caries in children using robust data linkage between a national survey and routine population-wide dental inspection data.

The strengths and limitations of this study need to be considered. Firstly, the linkage between datasets was robust, with a high linkage rate that did not exclude many records. The GUS cohort slightly overrepresented families from less deprived areas, as is common for opt-in studies. However, the relatively large sample allowed thorough comparisons within each SIMD group. The analysis was cross-sectional, and therefore the impact of child age on proxy-reporting accuracy could not be assessed, with reporting accuracy believed to alter depending on the age of the child (Parsons *et al.*, 2012; Imes *et al.*, 2021). Another limitation is that exact dates (day/month) of GUS survey responses were not available due to information governance constraints, and it is possible the data for GUS may have been collected before or after NDIP leading to misclassifications, however, it is

not expected these would be socially patterned. In both scenarios it is unlikely that visible decay would develop in a short period of time within a single school year, but the possibility should be considered. The use of 'basic' NDIP inspection could be seen as a limitation, however the findings derived from the 'basic' inspections, closely mirror the data obtained from more comprehensive 'detailed inspection' assessments (Macpherson *et al.*, 2020). The latter involves a 20% subsample of the population and employs the more thorough British Association of Community Dentistry (BASCD) criteria, particularly the decayed, missing, and filled teeth (d3mft) index (Pine, Pitts and Nugent, 1997). Another possible limitation of using NDIP data is that some private/public school children are not included (approximately 5%), this could lead to an overestimation of caries experience overall but would have limited impact on the current study. Furthermore, the current study was conducted on children born in 2004, with caries experience data collected in 2009/10. Given the time passed, there is a possibility that parental awareness of children's oral health issues now is greater than when data for the current study was collected. This could lead to the sensitivity being higher in more recent cohorts. However, our finding that parents from less deprived areas are less likely to accurately report caries experience in their children suggests that social desirability is a factor, and it is unlikely to be solely an awareness issue. Lastly, the use of SIMD, an area-based socio-economic measure, as a proxy for individual level socioeconomic circumstances comes with both strengths and limitations. It is extensive, robust, very well documented and it's 38 indicators cover a plethora of socioeconomic factors. However, due to the composite nature of this indicator, it is not possible to identify individual patient-level information and may lead to the risk of ecological fallacy (Scottish Government, 2009).

In conclusion, parent/carer proxy-reporting of caries experience in 5-year-old children had very low sensitivity and was lowest in children from the least deprived areas. In contrast, parents/carers who reported their child had caries experience did so reasonably accurately. Proxy-reported surveys are not sufficiently sensitive to replace trained/standardised clinician examination measures in assessing dental caries experience in child populations of this age group and highlights the importance and benefits of data linkage to routine data sets.

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