Observational Studies

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Social deprivation and paediatric chronic pain referrals in Ireland: a cross-sectional study

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Abstract

Objectives: Social deprivation is associated with a higher prevalence of chronic pain in children and an under-representation in specialist paediatric chronic pain programs. Our primary objective was to determine if there was a relationship between social deprivation and paediatric chronic pain referrals in Ireland. Secondary objectives included analysing for differences between deprivation groups in pain characteristics and function that are recorded at first clinic visit.

Methods: Families attending the national paediatric complex pain service in Dublin, Ireland, complete questionnaires on pain characteristics, parental pain catastrophizing, and pain-related disability including sleep quality and school attendance. We retrospectively reviewed records from between February 2016 and November 2019 on 288 patients. Social deprivation was assessed using the Pobal HP Deprivation Index, which is based on data from the Irish national census.

Results: Referrals followed a normal distribution across deprivation grades. Children in the disadvantaged group had a longer duration of pain, greater use of screens at bedtime, and longer sleep onset latency. Parents in the disadvantaged group had significantly higher levels of parental pain catastrophizing.

Conclusions: In Ireland, while paediatric chronic pain referrals were normally distributed across deprivation group, the disadvantaged group was different in several ways that may be clinically significant. Further work will be needed to determine the longitudinal relationship between these factors before and after the referral and initial review. Screening for, and targeting, potential risk factors for pain chronicity may be needed to harmonize treatment outcomes in children from socially disadvantaged families.

Keywords: chronic pain; paediatric pain; pain catastrophizing; sleep quality; social deprivation.

Introduction

Paediatric chronic pain is ideally managed within a biopsychosocial framework [1]. However, the family's socioeconomic status (SES) can determine access to paediatric chronic pain services [2, 3]. Financial hardship in childhood is longitudinally associated with developing chronic pain in adulthood [4] and a cross-sectional relationship between low SES and chronic pain in childhood is emerging [5, 6]. A mediating effect of geographic distance on SES for access to specialist paediatric pain centres has been described in two European countries with differing healthcare systems [2, 3]. Extramural influences outside a household unit, e.g., population density, can modify socioeconomic influences [7].

Social deprivation is described as the inability to fully and normally interact with wider society. However, this may have different meanings between and within societies, e.g., urban vs. rural deprivation. Composite indices of social deprivation have evolved from unidimensional scores of material deprivation [8, 9], to multidimensional scores [10], utilising weighted domains such as health, education, skills and training, housing, geographic access, and crime. The operational definition underpinning the deprivation index in this study is from a review of such indices which posits that "the implication of the term deprivation is of an absence; of essential or desirable attributes, possessions, and opportunities, which are considered no more than the minimum by that society" [11].

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Rural deprivation in areas is largely linked to the concept of deprivation of opportunities, which cannot be captured in measurements that rest with individuals alone. This retrospective cross-sectional study of referrals to a national paediatric chronic pain service in Ireland specifically investigated the following: (1) the distribution of referrals based on deprivation index; (2) the association between deprivation index and differences in other variables recorded at the first clinic visit.

Methods

Participants

Following institutional ethical approval (REC: GEN/677/18), we performed a retrospective, cross-sectional analysis of referrals to the national paediatric complex pain service in Dublin, Ireland. This service sees children and young people in the Republic of Ireland up to the age of 18 years who have complex or persistent pain.

Complex pain assessment form

Prior to the first clinic appointment, children and their parents complete a complex pain assessment intake form. In addition to patient demographics, pain aetiology and duration, pain intensity and parental estimates of children's pain intensity and coping ability are recorded on 11-point 0–10 numerical rating scales (NRS). There are three questions relating to pain intensity over the previous two weeks: pain out of 10 "on average", "at its worst" and "at its best". For children, we report the results of all three scores and for parents estimates of child pain, the results to "pain on average". Questions related to sleep quality were based on the domains of the Pittsburgh Sleep Quality Index [12]: self-reported sleep onset latency (<30, 30–60, >60 min) and pain-related sleep disruptions, asked as percentage of wakings due to pain. We also asked about the use of use of digital devices immediately before bedtime. The impact of pain upon school attendance is recorded by self-report, as number of days missed and percentage school attendance. Pain interference with social activities is recorded as a self-reported 11 point 0–10 NRS "0 – no interference" to "10 – completely interferes". We also administer the Pain Catastrophizing Scale-Parent (PCS-P) [13] for parents to complete.

Deprivation index

Social deprivation was assessed using the Pobal HP Deprivation Index [14]. This index provides a method of analysing affluence and deprivation by geographical area derived from data from the National Census of Ireland, which is undertaken every five years. The current version of the HP Index is based on data from the 2016 census wave. The HP Index is based on geographic units called small areas (SAs), each of which are uniform in size, with a mean of approximately 100 households, and are relatively homogenous in social composition. The HP Index is based on three dimensions: demographic profile, social class composition, and labour market situation. Absolute and relative index scores may be calculated. Absolute Index Scores are used to calculate longitudinal changes in geographical areas between census waves. The Relative Index Scores are specific to that census wave and are rescaled to have a mean of zero and a standard deviation (SD) of 10. The scores follow a normal distribution in eight categories from 'extremely affluent' (>3 SD above the mean), to 'extremely disadvantaged' (>3 SD below the mean). The Relative Index Score and corresponding deprivation category for each participant were determined by entering their postal zip code into the Pobal online portal. For the between-group analyses of associations with demographic and pain-related variables, we used cut-offs of >1 SD above the mean as 'affluent', <1 SD above or below the mean as 'average' and >1 SD below the mean as 'disadvantaged'.

Analytic strategy

The primary objective of this analysis was to determine whether social deprivation influenced access to care. To do this, we tested whether the total referrals followed a normal distribution across deprivation categories. We also looked for between-group differences in the duration of pain and first attendance at clinic. Secondary objectives included determining any additional between-group differences in factors associated with pain, such as age and sex, pain intensity, sleep hygiene, pain impact upon function, such as sleep quality, school attendance and social activities, and parental estimates of pain intensity, child pain coping and parental pain catastrophizing.

Statistical analysis

Datasets were tested for a normal distribution using the Anderson–Darling test and nonparametric tests were used where appropriate. For between-group differences, we used a Kruskal–Wallis test for continuous variables and a chi-squared test for categorical variables. Data is presented as median and interquartile range (IQR) unless otherwise stated. Significance was set at α=0.05 with correction for multiple comparisons on post hoc testing.

Results

Participants

We retrieved assessment sheets on 289 patients referred to the paediatric chronic pain service between February 2016 and November 2019. One patient was from outside the Republic of Ireland and was excluded from further analysis as we could not assign a deprivation index category. Patients (34% male) had a median age of 13 years (IQR 11–15 years) and had median average pain scores of 7 on a 0–10 NRS (IQR 5–10). The median duration of pain was 24 months (IQR 8–49.5 months). The three groups are summarized in Table 1.

Table 1: Characteristics of patients in each deprivation group.

			Affluent	Average	Disadvantaged	p-Value
Demographics			n=41*	n=190*	n=57*	
Age	Median (IQR)		14 (11–15)	13 (11–15)	14 (12–16)	0.06[a]
Sex	Male, %		16/41 (39%)	61/189 (32%)	20/57 (35%)	0.69[b]
Pain intensity						
0–10 NRS	Average		7 (6–8)	7 (5–8)	7 (5–8)	0.95[a]
	Highest		9 (8.5–10)	9 (8–10)	9 (8–10)	0.24[a]
	Lowest		3 (2–6)	4 (3–6)	5 (30)	0.11[a]
Pain duration						
Duration (mths)			24 (9–72)	22 (6–44)	36 (16–60)	0.01[a]
Pain-related disability						
Sleep	% Disruptions due to pain					
		<50%	11/33 (33%)	41/149 (28%)	6/46 (13%)	0.177[b]
		~50%	5/33 (15%)	31/149 (21%)	14/46 (30%)	
		>50%	17/33 (51%)	77/149 (51%)	26/46 (57%)	
School	Days missed		10 (5–26) (n=26)	15 (8–28) (n=120)	8.5 (4–19) (n=30)	0.07[a]
	% Attendance (median)		92% (n=12)	75% (n=54)	75% (n=15)	0.21[a]
Social	Interference: 0–10 NRS		7 (6–8.75)	7 (5–9)	8 (5.5–9)	0.38[a]
Parental measures			n=36	n=177	n=47	
Child's pain intensity	Pain intensity: average 0–10 NRS		7 (6–8)	6.5 (5–8)	7 (5–8)	0.65[a]
Child's pain coping	Pain coping ability: 0–10 NRS		6 (4–8)	6 (4–7)	6 (5–8)	0.48[a]
PCS-P	Total		28.5 (19.25–38.5)	28 (20–36)	36 (29–42)	0.0016[a]
	Rumination		12.5 (10–15.75)	12 (10–15)	14 (12–16)	0.0120[a]
	Magnification		4.5 (3–7.75)	4 (2–7)	6 (4–7)	0.0728[a]
	Helplessness		11.5 (6–17.75)	12 (7–16)	16 (12–21)	0.0009[a]

*Sample size for full group; for outcomes where data was not available for all participants, the number of participants (n=) is included below the result or stated where percentages are reported. [a]Obtained using Kruskal–Wallis test; [b]p values by Chi-squared test. IQR, Interquartile Range; NRS, Numerical Rating Scale; PCS-P, Pain Catastrophizing Scale-Parent version.

Access to care

An Anderson–Darling test indicated that the 288 referrals over four years to the paediatric complex pain service followed a normal distribution across deprivation categories, A^2=0.535, p=0.11 (Figure 1). There was however a significant difference in the median time from onset of pain to time of first review between deprivation groups, Kruskal–Wallis 8.7, p=0.013 (Figure 2).

Pain scores

Across the three deprivation groups, there was no difference in the medians of the 'lowest pain' scores, Kruskal–Wallis 4.37, p=0.11, 'pain on average' scores, Kruskal–Wallis 0.084, p=0.95, or 'highest pain' scores, Kruskal–Wallis 2.82, p=0.24.

Age & sex

There was no difference in median age across the three groups, Kruskal–Wallis 5.43, p=0.06. The proportion of male patients was 34% of the total referrals and a Chi-squared test of independence showed no difference between groups, x^2 (2, 288)=0.73, p=0.69.

Sleep hygiene

The median weekday bedtime (21.00 h, IQR 21.00–22.00 h) was not significantly different between groups, Kruskal–Wallis 2.89, p=0.23. The median weekend bedtime (22.00 h, IQR 22.00–23.00 h) was also not significantly different between groups, Kruskal–Wallis 4.71, p=0.09. Overall, 65% of children admitted to using screens or digital devices right before bed, which varied significantly between

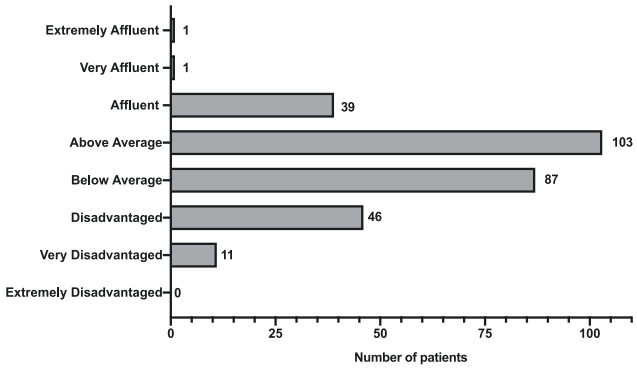

Figure 1: Distribution of relative index scores.
Relative index scores are rescaled to a mean of zero and standard deviation (SD) of 10. A total of 288 records were available to analyse. For between-group analyses, the eight deprivation categories were regrouped into affluent (>1 SD above the mean), average (<1 SD above or below the mean) and disadvantaged (>1 SD below the mean).

groups (58.5% of affluent vs. 87% of disadvantaged), Chi-squared x^2 (2,269)=12.21, p=0.002 (Figure 3).

With regard to self-reported sleep latency, the proportion of children reporting that it took over 60 min to fall asleep was significantly different between groups (21% of affluent vs. 50% of disadvantaged), Chi-squared x^2 (4,271)=10, p=0.04 (Figure 4).

Pain & function: sleep, school, social

The impact of pain upon sleep quality was assessed by asking whether the number of wakings from sleep that were due to pain was less than, equal, or more than 50% of all sleep disturbances. The frequency of pain-related sleep disturbance was not different across social deprivation groups, x^2 (4, 227)=6.3, p=0.177. School attendance was reported by parents as either number of days missed or percentage attendance and there were no significant differences between deprivation groups, Kruskal–Wallis 5.17, p=0.07 for days missed and Kruskal–Wallis 3.0, p=0.21 for percentage attendance. Pain interference with social activities did also not differ significantly between groups, Kruskal–Wallis 1.88, p=0.38.

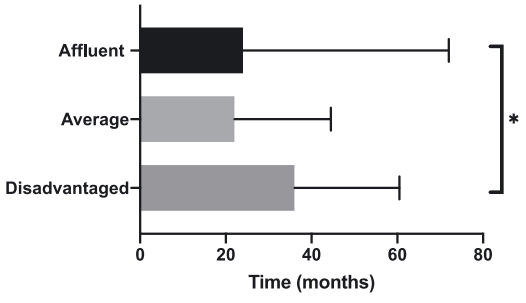

Figure 2: Deprivation group & pain duration when seen.
Disadvantaged group have pain for longer by time of first review. Median time from onset of pain to time of first review between deprivation groups, Kruskal–Wallis 8.7, p=0.013.

Parental estimates: pain intensity & pain coping

Parental estimates of average pain intensity, KW 0.85, p=0.65, and of their child's ability to cope with pain, KW 1.46, p=0.48, were not significantly different between groups.

Parental pain catastrophizing

PCS-P median total scores were significantly different between groups, Kruskal–Wallis 12.81, p=0.0016; on post hoc testing with Dunn's multiple comparison test, the difference was between the disadvantaged group and both affluent (mean rank difference, –41.23, p=0.04) and average (mean rank difference –43.73, p=0.001) groups. On examining between-group differences of each subscale of the PCS-P, the rumination (Kruskal–Wallis 8.8, p=0.01) and helplessness (Kruskal–Wallis 13.9, p=0.0009) subscales were significantly different across groups and on post hoc testing of each difference it was the disadvantaged group that was different from one or both of the other two groups (Figure 5).

A pre-print draft version of this manuscript has been available at the medRxiv site [15] https://www.medrxiv.org/content/10.1101/2020.02.24.20027037v1

Discussion

The deprivation scores of children referred to the national paediatric chronic pain service in Ireland were normally distributed, although children from the disadvantaged group had pain for longer by the time of first review. In other variables recorded at first clinic review, children from the disadvantaged group had a longer sleep onset latency and greater use of screens before bedtime while parents

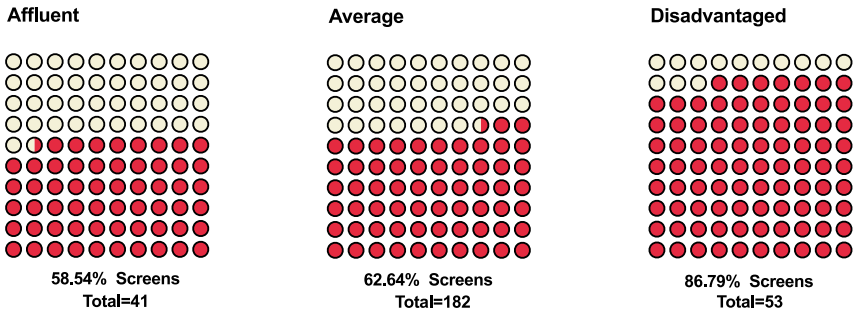

Figure 3: Deprivation group and use of screens before bed.
Overall, 65% of children admitted to using screens or digital devices right before bed, which varied significantly between groups (58.5% of affluent vs. 87% of disadvantaged), Chi-squared x^2 (2,269) =12.21, p=0.002.

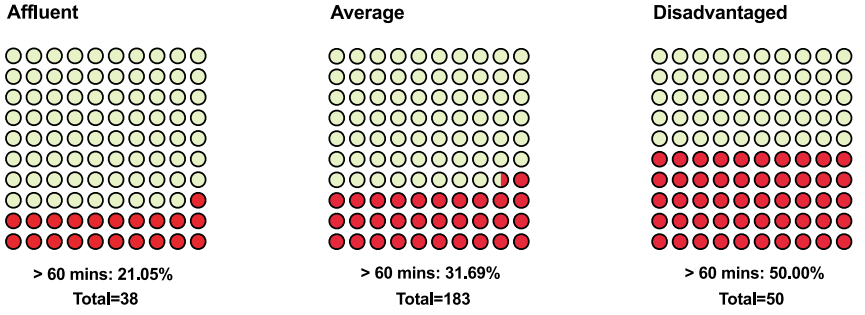

Figure 4: Deprivation group and prolonged sleep latency.
The proportion of children reporting that it took over 60 min to fall asleep was significantly different between groups (21% of affluent vs. 50% of disadvantaged), Chi-squared x^2 (4,271)=10, p=0.04.

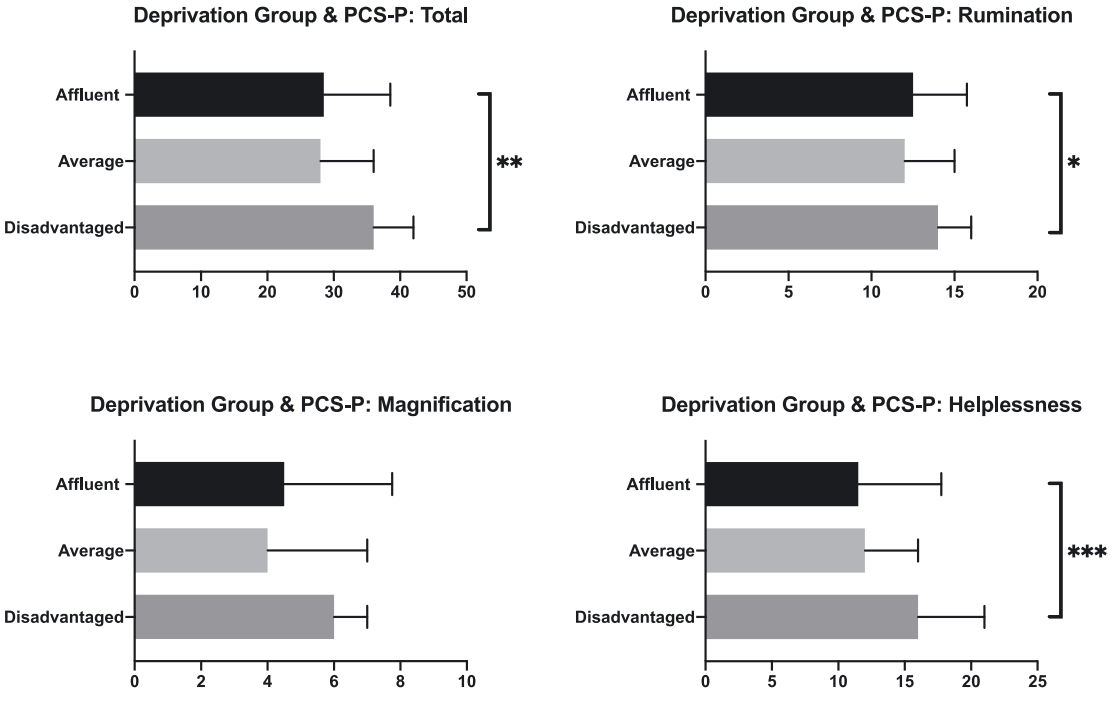

Figure 5: Deprivation groups and parental pain catastrophizing (PCS-P) scores.
PCS-P median total scores were significantly different between groups, Kruskal–Wallis 12.81, p=0.0016. On examining between-group differences of each subscale of the PCS-P, the rumination (Kruskal–Wallis 8.8, p=0.01) and helplessness (Kruskal–Wallis 13.9, p=0.0009) subscales were significantly different across groups.

from the disadvantaged group had higher pain catastrophizing scores, specifically on the helplessness subscale. Of note, it was the disadvantaged group that was different from the other two groups; on post hoc analyses, there were no significant differences between the average and affluent groups. It is also worth noting the similarities that existed across all deprivation groups. Pain intensity, age, sex and parental estimates of their child's pain and ability to cope with pain were not significantly different across deprivation groups. Outcome measures of pain-related disability such as school attendance, interference with social activities and pain-related sleep disruption were also similar across deprivation groups, which to our knowledge has not previously been reported.

Ireland is a geographically small country and this may mitigate the effects of travel distance on referral to a specialist service, as this has been identified as a factor in access in previous reports [2, 3]. The relative index scores of the HP Index are scaled to a normal distribution, whereas other measures of SES or deprivation may not be. While both these factors may account for the absence of a social gradient in our patient cohort, this does not imply that social deprivation is not associated with paediatric chronic pain at a population level. In studies of adults, chronic pain is more common in socially deprived areas, is associated with greater pain intensity and pain-related disability, and the economic burden of pain further compounds the initiating and maintaining factors of deprivation [16]. Social deprivation and lower socioeconomic status are associated with a greater risk of children experiencing 'adverse childhood experiences' (ACEs) [17], which have a well-described association with negative health outcomes later in life [18]. Children with ACEs are at increased risk of developing chronic pain in a dose-dependent manner, although some individual ACEs, such as financial hardship, living with a mentally ill adult, and experiencing discrimination based on race, have a stronger association with pain[19]. Although chronic pain is common, affecting approximately 20% of children and young people, only 5% of children experience pain with major limitations of function that requires multidisciplinary input [20]. There are differences in the frequency of ACEs reported in different treatment settings, which may indicate that ACEs may be a barrier to children accessing recommended outpatient treatment before presenting to multidisciplinary pain rehabilitation[21], i.e. they may have a different trajectory through a treatment pathway with restrictions at different points along it. Similarly, our finding of normally distributed social deprivation grades for pain referrals may therefore not be representative of the relationship between social deprivation and paediatric pain at a population level due to challenges in accessing care for disadvantaged families. The longer duration of pain in the disadvantaged group may reflect such differences in interacting with the healthcare system. Solely focussing on ACEs in this context may also be falsely reassuring if they are absent, as social deprivation encompasses the absence of positive opportunities as well as the presence of negative influences.

The Irish healthcare system, with which children and families interact, is a hybrid combination of state funding and private health insurance and 45% of the Irish population have some form of private health insurance [22]. While primary care in Ireland is free at the point of access for children under the age of six [23], chronic pain is uncommon in this age group. Older children and young people, who are more likely to have chronic pain, are charged a fee for each primary care visit, which in addition to other factors such as availability of public transport, may mean that disadvantaged families delay or ration seeking medical care. In secondary care, the situation is further compounded by waiting lists due to capacity issues in public hospitals. In 2020, approximately 10% of children and young people were on waiting lists for treatment in Irish public hospitals [24], therefore families with private health insurance seek treatment in private healthcare facilities. In public hospitals, patients with insurance have the option of opting in or out of using their insurance for different episodes of care. In what is termed 'two-tier queuing', the same patient and family may use their insurance to circumvent waiting lists for outpatient care and may then opt out of using their insurance for subsequent episodes of inpatient or ongoing outpatient care following the initial review. This may explain why there are not significant differences between the affluent and average groups in the duration of pain prior to initial review and why it is the disadvantaged group which is different from the other two groups. Our service does not routinely record insurance status and, due to the options of selectively using their insurance for different episodes of care, doing so would be logistically challenging in a retrospective review. Our service triages patients based on clinical priority, however that does not extend to other aspects of their interactions with the healthcare system. Ours is a single service across two academic tertiary paediatric hospitals and accepts referrals from primary, secondary, and tertiary care clinicians for young people up to the age of 18 years of age. Priority is based on emergent or established functional disability in physical, emotional, and social functioning, including the impact of pain upon school attendance, mood, and sleep quality [25]. Due to a differential distribution of specialist paediatric services and historical referral patterns, one clinical site receives a greater

proportion of referrals from primary and secondary care from other regions in the Republic of Ireland, while the other clinical site receives a greater number of referrals from other specialists within that tertiary care centre. In the 2016 census wave, there were 1,251,796 children and young people under the age of 18 years living in the Republic of Ireland [26]. Previous work on the prevalence of paediatric chronic pain in Irish children aged 9–12 years reported a prevalence of chronic pain of 9%, which was associated with an incremental increase in family healthcare costs of up to €500 per year [27]. Based on data from other countries, we would expect a higher prevalence of chronic pain of approximately 20% in older post-pubertal children and young people. There were 371,588 children aged 12–18 in the 2016 Irish census. Applying the estimate that 5% of those have chronic pain with significant functional disability [19], this equates to over 18,500 children who would be in need of multidisciplinary input. This contrasts significantly with the 289 children referred to our outpatient clinic over almost four years. There are other avenues available to referrers, such as adult pain clinics for young people over 16 years of age, and the paediatric specialities such as rheumatology, neurology, and gastroenterology, for musculoskeletal pain, headache, and functional abdominal pain respectively, in both the public and private healthcare systems in Ireland. Children may have attended these services first prior to attending our service; this is mostly ad hoc, although shared clinical pathways are emerging, e.g. between paediatric neurology and the pain service for the management of refractory headache. Of note, this data collection also did not capture consults and reviews by our pain service while patients were inpatients under the care of other specialists. Nonetheless, this represents a significant gradient between population estimates of paediatric chronic pain and those referred to our service. Challenges in access to specialist paediatric chronic pain services is not a phenomenon that is limited to Ireland [28].

The rate of screen use before bed in the affluent and average groups is comparable to previously reported rates of 60% in adolescents [29, 30]. The greater use of screens in lower income families and association with prolonged sleep onset latency have previously been reported and may not be specific to children with pain [31]. Given the similar bedtimes and rates of school attendance across deprivation groups, a longer time to sleep onset in the disadvantaged group would imply a shorter sleep duration, although this was not directly questioned. Shorter sleep duration is associated with emotional and behavioural problems, suicidal ideation [32] and may precede the onset of depression [33] Poor sleep may predispose to pain, pain chronicity and worsen pain-related disability [34]. The relationship between poor sleep quality and pain may be mediated by low mood and anxiety [35]. Longer sleep duration is associated with greater daytime activity in adolescents with chronic pain [36]. Pain catastrophizing, a construct consisting of rumination, magnification and helplessness, by parents has been identified as influencing pain intensity, pain-related distress, and disability in children with chronic pain [13] and recent work has suggested that this effect is mediated through child catastrophizing [37]. In adults, associations between lower socioeconomic status and higher levels of pain catastrophizing have been reported in patients undergoing knee surgery [38]. In our clinical cohort, the most significant difference was in the helplessness subscale. One explanation for this may be the diagnostic uncertainty faced by children and their parents [39], especially prior to first review at a chronic pain clinic. The longer duration of pain the disadvantaged group may also be a contributing factor. Children awaiting review frequently have increased emergency department attendances and emergency admissions in the years leading up to review, which then abate after pain clinic attendance [40]. Therefore, the first pain clinic appointment may coincide with a more prolonged period of stress and uncertainty in unfamiliar environments. Reductions in both parent and adolescent pain catastrophizing have been reported between first and second clinic visits [41]. We had elected to only measure parental catastrophizing so as not to overburden children with forms to complete prior to review. Repeated measures of parental protective behaviours, child pain catastrophizing and a more detailed and validated sleep quality questionnaire would aid in model-building to reproduce and generalize these findings. However, to our knowledge, this is the first study to identify poor sleep quality and higher levels of parental pain catastrophizing in children with chronic pain who are from a socially deprived background, as these are factors that may influence therapeutic outcome. If poor sleep quality and greater parental catastrophizing are more prevalent in socially disadvantaged groups at a population level, we would expect a higher prevalence of chronic pain in these groups. Following on from this, we would therefore expect a greater number of children referred to the pain clinic, assuming all other factors governing interactions with healthcare to be equal across deprivation grades.

Limitations of this study include its retrospective and cross-sectional nature and reliance on self-reported measures, so we can only report associations, not infer causation. The HP Deprivation Index is specific to Ireland, and although relevant for integrating healthcare with education and housing in an Irish context, it may not be generalizable to other countries. Longitudinal sampling after the initial consultation would help determine the

mediating effects in the relationships between sleep, pain catastrophizing and pain, pain-related disability and their influence on clinical outcome. The other major limitation is that the children referred to the pain clinic may represent a survivorship bias and may not be representative of children with pain in each deprivation grade at a community or population level.

Conclusions

In the Irish healthcare system, while referrals to the paediatric chronic pain service were normally distributed by social deprivation grade, the disadvantaged group is different from the others in several ways that may influence treatment outcome. Screening for, and targeting, the higher rates of pain catastrophizing and poor sleep hygiene may be needed to harmonize treatment outcomes across deprivation grades.

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Author contributions: EM: study design, data collection, first draft of article, final approval, complete accountability; MM: study concept, pilot study, revising of article, final approval, complete accountability; NOK: patient recruitment, revising of article, final approval, complete accountability; KMcC: study design and data analysis, drafting of article, final approval, complete accountability.

Competing interests: The authors declare that they have no conflict of interest.

Informed consent: Not applicable.

Ethical approval: The study received institutional ethical approval (REC: GEN/677/18).

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