Carer evaluations of paediatric epilepsy services with and without Epilepsy Specialist Nurse provision

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Abstract

Purpose. To compare paediatric epilepsy services with and without Epilepsy Specialist Nurse (ESN) provision on measures of carer satisfaction and accessibility of service.
Methods. In Study 1, carers in Northern England (n = 69 with an ESN, n = 27 without an ESN), completed the Parent Report of Psychosocial Care Scale to measure satisfaction with service provision. A measure of accessibility of service was also included. In Study 2, in depth semi-structured interviews with 58 carers (51 of whom had also participated in Study 1) were examined for talk related to accessibility of service.
Results. In Study 1, Satisfaction with service levels were high across all areas, (ESN areas *Mdn* = 9.04, *IQR* = 1.48, non-ESN areas *Mdn* = 8.29, *IQR* = 2.41; maximum score = 10), but with carers from ESN areas over 3 times more likely to endorse scores at the median or above relative to non-ESN areas (*OR* = 3.28). For accessibility, carers in ESN areas were over 5 times more likely to have a median score or higher (ESN areas *Mdn* = 10, *IQR* = .45, non-ESN areas *Mdn* = 8.4, *IQR* = 5, *OR* = 5.43). In study 2 a majority of all carers reported having made at least one attempt to contact services between appointments, for a wide range of reasons, with timely resolution reported in ESN areas, but more variable resolution occurring in non-ESN areas.
Conclusion. Paediatric ESNs provide a critical and timely service to children with epilepsy and their carers.

Key words: Children with Epilepsy; Epilepsy Specialist Nurse; Paediatric epilepsy services

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Childhood epilepsies are a family of neurological disorders defined not only by propensity to unprovoked seizures but by potential neurodevelopmental and mental health comorbidities[1], together placing a psychosocial burden on the child with epilepsy and their families[2-4]. Optimal management of health service delivery in the UK context, according to the National Institute of Clinical Excellence (NICE) guidelines[5], comprises timely access to a paediatrician with a special interest in epilepsy as well as a paediatric ESN. Together, these professionals manage diagnosis and ongoing treatment, as well as liaison with tertiary paediatric neurology, psychology, speech therapy, education and social services as required[6-7]. A key component of this service model, the paediatric ESN, was only available to approximately half of treatment units, according to an audit conducted in 2012[8], although this access has improved, with 69% of families having access to ESNs in the 70% of health trusts participating in a recent audit update[9].

Research evaluating the impact of ESNs has focused on adult services. A recent Cochrane review including 7 studies of ESN interventions[10] found there was evidence of positive effects on patient's knowledge of epilepsy, with weak evidence for positive impacts on quality of life. There were no differences between intervention and control groups on seizure frequency, or anxiety and depression measures. Given the need for specialist psychological intervention to treat comorbidities such as anxiety and depression[11], these clinical outcome measures may not be the most applicable to ESNs. In terms of satisfaction with health services, studies in Norway[12] and Ireland[13] report higher satisfaction among patients receiving services including an ESN. In depth interview studies by Ridsdale and colleagues[14] in the UK also found multiple and varied examples of specific help offered by ESNs in adult services.

In Study 1, we sought to evaluate carer's experiences of services with and without paediatric ESNs by use of the Psychosocial Needs of Carers questionnaire, an instrument developed and validated by Austin and colleagues[15] designed to measure both satisfaction with care received, as well as degree of unmet needs, in carers of children with epilepsy. We predicted that level of unmet need would not differ between groups, as childhood epilepsy presents different challenges as development progresses[16]. We did predict that levels of satisfaction with services would be greater in areas with a paediatric ESN. Additionally, we asked participants about ease of access to doctors/nurses if they had a question in between regular clinic appointments, as this accessibility is so central to the work of ESNs[6, 17], predicting that scores on accessibility would be higher in areas with ESNs.

Study 1

Method

Participants.

Participants were the parents/carers of children diagnosed with epilepsy[18] on the caseload of paediatricians in five UK health trusts (i.e. administrative health areas). Three of the areas had ESN provision (Table 1). The main criterion for selection of area was commutable distance from the research base, as the interview

arm of the study was conducted in the homes of participants. There were a further 5 trusts that were at commutable distance, that did not opt to participate in the study, all of which had ESNs. Both ESN and non-ESN areas had at least one paediatrician with a special interest in epilepsy (involving enhanced training provided by the British Paediatric Neurology Association), who had their own epilepsy caseload, as well as providing advice on epilepsy to other paediatricians in the health trust. All the children with epilepsy within a participating trust were screened for study eligibility (Figure 1). Participants whose children were already recruited to an intensive national anti-epileptic drug (AED) study were excluded, as were carers who required translation services, due to funding limitations. Participants were recruited by an invitation letter. They were initially informed that the study concerned all aspects of service provision, and were only debriefed that the study had a focus on ESN provision once their participation was over. The full study had three components, the questionnaire component, an in-depth interview, and a consultation recording. Participants could select to participate in all components, or just one. All participants provided written consent and the study was approved by a National Health Service (NHS) Research Ethics Committee in February 2015, after which recruitment started, with recruitment closing in September 2017. Once participants had consented to the questionnaire component of the study, if they had not returned the questionnaire within a 6-week period, they were sent a reminder via text. If this failed, a second copy of the questionnaire was posted to their home, in case the first had been lost, together with a hand-written explanatory note.

In order to detect a medium effect size at 80% power, a sample size of 64 participants in each of the ESN and non-ESN groups was aimed for. This did not factor in any measure of intra-cluster correlation coefficients arising from the use of different areas[19], as we had no basis to estimate these. Ninety-six parents/carers provided questionnaire data out a total of 554 that were eligible (Figure 1; Table 1). While the target number for ESN area participants was met (n = 69), that for non-ESN areas was not met (n = 27).

Design.

The study employed a quasi-experimental nonequivalent groups posttest only design. The factors were the 5 different service areas, as well as these areas recoded as an ESN factor (ESN and no-ESN). The dependent variables were the scores on the Satisfaction with Care Received sub-scale of the Parent Report of Psychosocial Care Scale[15] (PRPCS), the scores on the Remaining Needs for Information and Support sub-scale of the PRPCS, and the score received concerning accessibility of clinicians in between regular appointments. Each participant was sent a questionnaire on one occasion, approximately 2 weeks after their attendance at their regular consultation with their paediatrician, following their consent to participate in the study. The regularity with which these appointments occurred varied between participants, being at 3, 6, or 12 month intervals, depending on level seizure control. Therefore for some participants there was a relatively large interval between consenting to participate, and receiving their questionnaire, but it seemed preferable to approximately equate time interval since last contact with service among participants.

Measures.

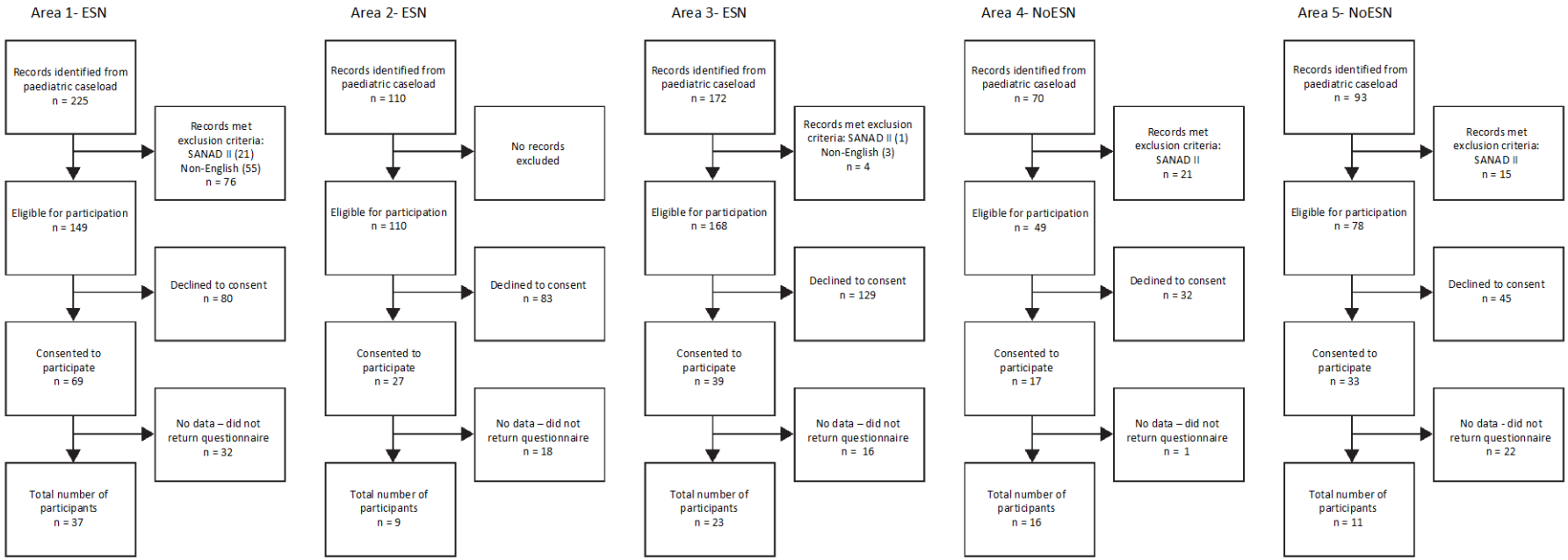
An adapted version of the PRPCS[15] was utilised (Appendix S1), whereby the original categorical response options were replaced with a 10 cm visual-analogue scale[12] (VAS). The Satisfaction with Care Received subscale contains 8 questions, concerning whether doctors/nurses provided sufficient information on seizure handling, AEDs, school liaison, emergency procedures, as well as addressing concerns. The sub-scale on remaining needs for information and support comprises 14 questions, covering needs for information on handling the epilepsy, concerns for the future, and mental health support. A further question on accessibility of doctors/nurses between regular appointments was added with responses also utilising a 10 cm VAS scale.

Data analysis.

All responses were scored by manual measurement by a researcher blind to participant, area and the research hypotheses, with a randomly selected 10 checked for accuracy, with 100% agreement obtained (+/-1mm). The total score for the Satisfaction with Care Received sub-scale was the mean score of the 8 questions. There were 10 participants with missing data on the question concerning service in relation to schools, as this only applied to school-aged children. In these cases, the total Satisfaction with Care Received score was the mean of the remaining 7 questions. The total remaining needs for information and support score was the mean score for the 14 questions comprising this subscale. The question concerning accessibility of service in between regular appointments was analysed as a separate dependent variable.

In order to address the question of whether either the independent variable of Area or presence of ESN was related to scores on the PRPCS subscales, or accessibility between appointments, our original analysis plan was to adopt a general linear modelling (GLM) forward-fitting approach, whereby Area would be entered as a factor, and this model compared with the intercept using the Bayes Information Criterion (BIC). Then, an intercept plus ESN model would be run, and the BIC compared to the model containing intercept and Area. If Area or presence of ESN had no effect on scores, then the intercept model would have the lowest BIC score, whereas if either Area or the ESN factor had the lowest BIC score, then whichever provided the model of best fit would be accepted. Such a comparison of models is required as it is possible that areas reliably differ from each other for reasons other than the presence of an ESN. However, due to the negative skew in the data because of the frequency of ceiling scores, the residuals of the models of all 3 dependent variables were not normally distributed, thus violating the assumptions underlying GLMs. Therefore, the data was transformed to take a binary form, with scores either being below the overall median, or equal to and above the median score. The models were then run using logistic regression, following the forward-fitting approach outlined above.

Figure 1.
Recruitment across the participating areas for Study 1.



Note. There were 70 local authority looked after children in the area 2 caseload and 8 in area 3. As there was no stable principal carer for these children, and no individual who could consent to participate, we could not proceed further with the study in these cases. SANAD II = Standard and New Antiepileptic Drugs (UK) II AED trial.

Table 1.

Characteristics of ESNs, carers and their children with epilepsy across participating areas

	Area 1-ESN (*n* = 37)	Area 2-ESN (*n* = 9)	Area 3-ESN (*n* = 23)	Area 4-NoESN (*n* = 16)	Area 5-NoESN (*n* = 11)
ESN information[a]					
Years in role	9.5	2.5	1.5	-	-
Working time equivalent	1.0	0.5	0.5	-	-
Carer information					
Relationship to child, *n* (%)					
Mother	34 (91.89)	8 (88.89)	22 (95.65)	16 (100)	10 (90.91)
Father	3 (8.11)	1 (11.11)	1 (4.35)	-	1 (9.09)
Ethnicity, *n* (%)					
White British	32 (86.5)	7 (77.8)	20 (87.0)	16 (100)	10 (90.9)
Asian British	5 (13.5)	2 (22.2)	2 (8.7)	-	1 (6.3)
Declined to answer	-	-	1 (4.3)	-	-
Characteristics of child with epilepsy					
Gender, *n* (%)					
Male	26 (70.3)	6 (66.7)	13 (56.5)	8 (50.0)	4 (36.4)

Female	11 (29.7)	3 (33.3)	10 (43.5)	8 (50.0)	7 (63.6)
Age, y:mo					
M (*SD*)	8:7 (4:4)	9:1 (4:9)	9:9 (5:3)	9:8 (4:1)	7:10 (5:2)
Age of onset, y:mo					
M (*SD*)	4:5 (3:9)	2:11 (3:1)	6:1 (5:4)	4:9 (3:8)	5:0 (4:3)
Epilepsy Type, *n* (%)					
Focal	16 (43.2)	-	6 (26.1)	5 (31.3)	4 (36.4)
Generalised	19 (51.4)	3 (33.3)	8 (34.8)	10 (62.5)	6 (54.5)
Combined Focal & Generalised	2 (5.4)	6 (66.7)	9 (39.1)	1 (6.3)	1 (9.1)
Aetiology, *n* (%)					
Genetic	3 (8.1)	4 (44.4)	1 (4.3)	1 (6.3)	-
Structural	2 (5.4)	-	2 (8.7)	1 (6.3)	2 (18.2)
Genetic/Structural	4 (10.8)	-	1 (4.3)	1 (6.3)	-
Infectious	1 (2.7)	-	-	1 (6.3)	-
Unknown	27 (73)	5 (55.6)	19 (82.6)	12 (75)	9 (81.8)
Seizure Frequency, *n* (%)					
Daily	7 (18.9)	1 (11.1)	4 (17.4)	-	3 (27.3)

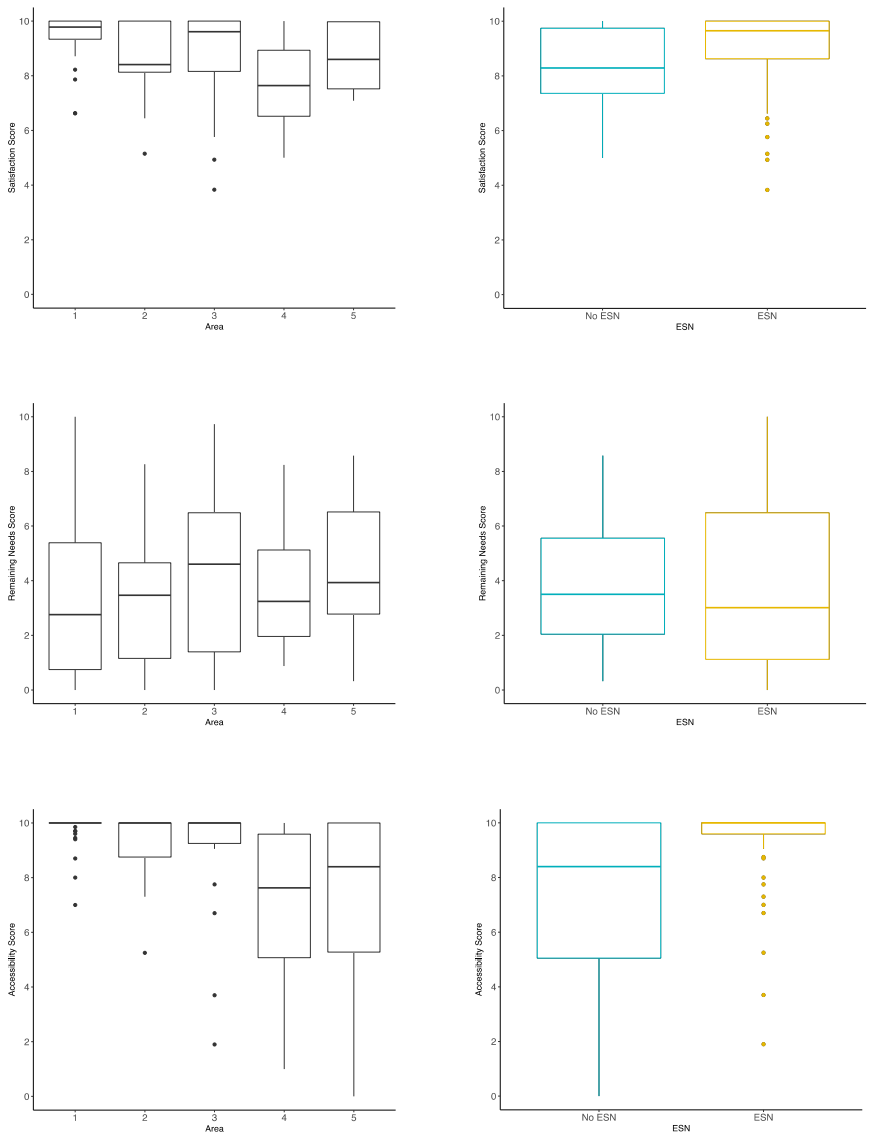
Weekly	4 (10.8)	4 (44.4)	3 (13.0)	-	2 (18.2)
Monthly	5 (13.5)	1 (11.1)	3 (13.0)	2 (12.5)	1 (9.1)
Less than monthly	21 (56.7)	2 (22.2)	13 (56.5)	11 (68.8)	5 (45.5)
Unclear	-	1 (11.1)	-	3 (18.8)	-
Antiepileptic medication, *n* (%)					
Monotherapy	23 (62.2)	4 (44.4)	13 (56.5)	14 (87.5)	9 (81.8)
Polytherapy	10 (27.0)	5 (55.6)	9 (39.1)	2 (12.5)	2 (18.2)
None	4 (10.8)	-	1 (4.3)	-	-
Comorbidities, *n* (%)					
Diagnosed	12 (32.4)	5 (55.6)	8 (34.8)	11 (68.7)	3 (27.3)
None reported	25 (67.6)	4 (44.4)	15 (65.2)	5 (31.3)	8 (72.7)

Note. Medical records were reviewed by research nurses, according to a template, to derive clinical data. [a]ESNs had all undertaken paediatric epilepsy training (PET) or equivalent accredited by the British Paediatric Neurology Association https://courses.bpna.org.uk/ . Additionally, Area 1 ESN was a nurse prescriber.

Results

Figure 2.

Medians and interquartile ranges for satisfaction with service score (top panel), remaining needs score (middle panel) and accessibility score (lower panel), as a function of Area (left panels) and the ESN factor (right panels).



Note. Areas 1-3 are ESN areas, and 4-5 are Non-ESN areas.

The reliability of the adapted PRPCS scale was good (Chronbach's alpha for the Satisfaction with Care Received subscale was 0.86 and for Remaining Needs was 0.94). Figure 2 shows the medians and interquartile ranges for satisfaction with service, remaining needs and accessibility scores. For the satisfaction with service scores, the ESN factor was the model of best fit, although there were only 1.8 BIC points between this model and the intercept only model, which was the next best model. For accessibility score, the model containing ESN as a factor was considerably better than the intercept only model (8.2 BIC points), which was the next best-fitting model. Remaining needs scores were similar across areas, and neither Area or the ESN factor added any explanatory power to the intercept only model. Table 2 displays the best-fitting models for satisfaction with service and accessibility scores. The full data set is provided in Appendix S3.

Table 2.
Parameter estimates for best-fit logit model of satisfaction score and accessibility score, with ESN as a predictor

Measure	Parameter	Estimate (β)	*SE*	95% CI	*p*	*OR*
Satisfaction Score	Intercept	-.88	.42	-1.69-(-.04)	.04	NA
	ESN	1.19	.49	.23-2.14	.015	3.28[a]
Accessibility Score	Intercept	-.87	.42	-1.69-(-.04)	.04	NA
	ESN	1.69	.5	.72-2.66	.001	5.43[b]

Note. The No-ESN group is used as the reference category in all analyses. All scores were recoded as binary variables (< median score, ≥ median score). [a]Small effect size[20]. [b]Medium effect size[20].

Discussion

Overall satisfaction with service levels were high across all areas, consonant with earlier findings[13, 17]. However, carers from areas with ESNs were over 3 times more likely to endorse scores at the median or above than carers from non-ESN areas. It is probable that our study underestimates the difference between ESN and non-ESN areas in terms of satisfaction scores, due to the difficulty of recruiting participants from non-ESN areas, an issue that also occurred in a recent national audit of paediatric epilepsy services[17]. In terms of remaining needs for information and support, scores showed high variability across all areas, and were unaffected by presence of an ESN[16].

A clear difference between areas with and without ESNs concerned accessibility between regular appointments. Williams et al.[17]found that the strongest predictor of carer satisfaction with service was accessibility. As these authors state, in order to understand this relation further, qualitative in-depth interview data is desirable. We decided to examine talk in our interview data specifically related to issues of accessibility of service between regular appointments. This had not been part of our original analysis plan, and thematic analysis of the interviews relating to service experiences will be published in subsequent papers. We had expected higher recruitment for the questionnaire study, but lower recruitment for the in-depth interviews, than actually occurred. As 58 carers participated in the in-depth

interviews, of which 51 had also returned questionnaires, this provided us with an opportunity to examine in detail what experiences underpinned the differences in scores on accessibility found study 1.

Study 2

Transcripts from the interview arm of our study were examined to address the issues of the proportion of participants who had attempted contacts with services in between regular appointments, the types of issues that led to these contact attempts, and whether accessibility of service between regular appointments was spontaneously cited as being either what was good or what could be improved about the service people had received (see Appendix S2 for interview schedule).

Method

Participants.

There were 58 participants, 51 of whom had also returned questionnaires (see Figure S1 in supplementary material for recruitment information). The majority of interviews were conducted by the first author, REB, supplemented by CW and ARL. Interviews lasted approximately 1 hr and were audio-recorded. A professional service was used for transcription, with transcripts then being checked and anonymised by REB.

Analysis.

Transcripts were examined for any talk related to needing to contact epilepsy services in between regular paediatric appointments. In 50 out of the 58 interviews, the issue arose without a direct query on the part of the interviewer, with the interviewer seeking clarifications as necessary. In the remaining 8 interviews, the interviewer asked an explicit question about whether there had been a need to contact services between appointments. The excerpts were analysed with regard to the nature of the triggering problem, and the contact pathway the participant followed.

Towards the close of the interview, participants were asked what they felt was good, and what could be improved, about the service they had received to date. Responses were analysed with respect to whether contact with services between regular appointments was spontaneously cited, either in a positive or negative manner. Agreement on classifications was reached by discussion between REB, ARL and CW.

Results

Contact with health services in between regular appointments

A majority of respondents in all 5 areas reported one or more occasions where they tried to contact epilepsy services between appointments (range across the 5 areas 83-100%). For all respondents attempting contact, the triggering problem(s) were related to the medical management of the condition, such as seizure control, unexplained symptoms, obtaining medications and potential adverse drug reactions. Respondents additionally reported trying to contact services for educational, behavioural, psychosocial, and practical issues, such as travel (range across areas, 0-40%).

Table 3 shows the number and percentages of respondents in each area who tried to contact different types of professional within their service area, at least once between regular appointments. The professionals available were the ESN (if part of service) or other nursing input (hospital staff nurses in Area 4, community nurses from neighbouring trust in Area 5), a paediatrician (hospital- or community-based), the paediatric ward if there was open access arrangements, Accident & Emergency and the General Practitioner (GP). There were 6 instances of contact attempts that did not fit these categories (to the paediatric neurologist, 111 NHS helpline, epilepsy charity helplines and psychologist).

Table 3

Percentages of respondents (n in parentheses) in each area contacting different types of health professionals in between regular paediatric appointments

Area	ESN/Other nursing	Paediatrician	GP	Paediatric ward open access	Accident & Emergency
		ESN areas			
1 (n = 17)	100 (17)	41.2 (7)	-	17.6 (3)	5.9 (1)
2 (n = 6)	66.7 (4)	66.7 (4)	16.7 (1)	16.7 (1)	-
3 (n = 14)	57.1 (8)	78.6 (11)	7.1 (1)	7.1 (1)	-
		No ESN areas			
4 (n = 16)	56.25 (9)	68.8 (11)	6.3 (1)	50 (8)	18.8 (3)
5 (n = 5)	80 (4)	100 (5)	20 (1)	-	-

Where ESNs were available (Areas 1-3), extensive use was being made of them (Table 2), and respondents were reporting timely and effective interventions, as the 3 excerpts below illustrate. There were only 5 instances across the three areas where parents reported not getting a sufficiently timely response from the ESN, and one report where the parent felt insufficiently supported over a school-related issue. Reasons for not contacting the ESN, excluding instances where direct hospital access was the most appropriate course of action, included being unaware of the ESN being available/not having 'phone number (3 respondents), preference for the paediatrician (3), and maintaining contact with the service from an NHS trust in the adjacent region (1).

"And [he/she has] been, when I've had concerns about the medication… (ESN's name) was brilliant because [he/she would] ring me up or I'd ring [him/her] and say, "Listen if this is happening then I don't get it, is this right?"...[he/she] was really good at addressing that and if needed, [he/she would] re-prescribe something

different. There's been a real consistency since that very early stage really which has been fab.' (Area 1)

"[He/she is] really, really good. You can always ring [him/her]. ..We had a problem with our rescue drug, …When I went to pick the prescription up they gave me some needles. I was like, "What's this?"…the chemist said, "Oh, yes, they're for injections that you have to give into the mouth." I phoned (Name of ESN) at that point, …[he/she] went, "Don't do it… " "Let me research it, and I will get hold of a chemist that can get hold of a proper one for you."" (Area 2)

"[He/she] was really, really good. I put a claim in for Personal Independence Payment…and they knocked it back, and I've gone to appeal with it. And I didn't have long to get documents…[He/she] really went out of [his/her] way, did (Name of ESN). [He/she] got in touch with (Child's name)'s GP, and [he/she] got hospital notes together and everything, and [he/she] got the GP to do a report, and [he/she] got (Consultant's name) to do a report as soon as he came back, for me to forward on." (Area 3)

In the two areas without ESNs, other professionals were often taking on responsive roles. Notably, in Area 4, there was a greater proportion of respondents that had open ward access (Table 2). Historically, a staff nurse from that trust that had retired 2 years prior to the study, had developed an interest in epilepsy and combined her staff nurse role with what would be recognised as an ESN role, following patient's hospital discharge. Five respondents made reference to having contacted this nurse prior to her retirement. There were 3 respondents who reported 'phoning other staff nurses on the paediatric ward, months or years after discharge from the ward (2 for medical issues and one for an education-related issue). In Area 5, community nurses from a neighbouring Trust took on tasks such as school training, and 3 respondents reported trying to contact these community nurses for practical and educational issues, with one of these reporting not being called back for several days.

Considering the 16 respondents in the areas without an ESN who tried to contact their paediatrician between regular appointments, 4 of these noted the timeliness of the response, with one particularly noteworthy example:

"But, and they started coming more often as well, didn't they?...But, to be honest, we've had really good communication with our community paediatrician. And [he/she is] like, "If you just ring up at 8 o'clock in the morning and ask to be put through to me, I'm there at that time before my clinic starts if you've ever got any concerns or anything". So I could always ring [him/her] up. And [he/she] did adjust the medication over the phone and put me a prescription out if we needed it…" (Area 4)

For the remaining respondents, they would normally receive return calls within a few days, which for some respondents caused difficulties, depending on the nature of the issue. One respondent reported having to reach the paediatrician via the GP:

"I think it was always (Consultant paediatrician's name) that would say, 'That's not worked,' but you don't immediately get back into the appointment system; you have to go through the GP…he came out in hives all over his body…and it tells you take them off immediately and go to your GP…and then they would send a note through to the hospital, and in the meantime then you wouldn't be taking any drugs, because they'd tell you take him off them so then you'd wait for another appointment to see them." (Area 4)

Accessibility between regular appointments in evaluations of service

When respondents were asked about what they thought were the best aspects of the service they had received, 22 respondents (59.5%) from the 3 areas with ESNs cited accessibility between appointments. When it came to aspects of the service they thought could be improved, only 7 respondents (18.9%) cited accessibility. In one case, the respondent cited accessibility as the best part of the service, but then also cited being able to contact someone during the ESN's annual leave as the way the service could be improved.

For the 2 areas without an ESN, 14 respondents (66.7%) cited accessibility as the best aspect of the service, but then 11 (52.4%) also cited accessibility as the aspect of the service that could be improved. Eight respondents cited accessibility both in what was best about the service and what could be improved, often because they had had contact with the retired staff nurse who had acted in an ESN capacity in Area 4, but were then no longer having that contact. Below are examples of how accessibility was cited for what was best about the service (first quote), or what could be improved most (third quote), with the second quote illustrating the comparison between previous and present service in Area 4.

"(name of ESN). Having that contact. Nurses have a different way of... I don't know. (name of Consultant) is lovely, I really like [him/her], but …It's nice to have that contact with somebody like (name of ESN) who has worked…as an epilepsy nurse, and having that knowledge on the end of the phone is just second to none really." Area 1

"Best things? Having (name of retired staff nurse acting as ESN) …It would be better if there were somebody who wasn't a shift worker, ideally like the nurse for the breast cancer… Yes more full-time that you wouldn't feel like you were interrupting the work of being a paediatric nurse… That is a big, big help just knowing that there is somebody that you can ring up... I think that is probably the best thing that there has been." Area 4

"I think having somebody in the community, one or two nurses that you can approach and speak to regarding, just your basic things about epilepsy. And having somebody who can go in and train people, because I think that was just absolutely ridiculous that there was nobody there, a service that should be there that is around the country, a nurse could have gone in." Area 4

Discussion

The majority of respondents had made at least one attempt to contact services between regular appointments, for multiple issues, often requiring a quick response, as was reported for adult services[14]. For two out of the three ESN areas, the ESN was fielding a majority of these contacts. In area 3, which had a relatively large caseload, the ESN had only been in post for 18 months, and had not yet had a chance to have contact with all the families. In the areas without ESNs, other professionals, such as paediatricians, staff nurses and nurses from other trusts were often trying to meet the needs of carers by taking on extra duties outside their normal roles. There was some variability in how timely interventions were, as well as the routes available to access help, in these areas.

A majority of respondents spontaneously cited accessibility as the best part of service provision in both ESN and non-ESN areas, demonstrating the importance of this factor[17]. The two types of areas differed in terms of accessibility being cited as what most needed improving, where it was only in the non-ESN areas that a majority of respondents nominated accessibility. These apparently paradoxical results can be explained by carers in area 4 noting the difference in provision since the retirement of a staff nurse who had acted as a *de facto* ESN.

General Discussion

Our quantitative and qualitative data indicate that service models that include a paediatric ESN generate higher levels of carer satisfaction. An important contributing factor to this result concerns accessibility of service when issues arise outside of regular clinic appointments. Our conclusions are limited by our relatively small sample for the questionnaire study, particularly from non-ESN areas. Despite this caveat, to our knowledge our study is the first to compare ESN and non-ESN services directly within the paediatric field, and results are consistent to those in adult services[12, 13], favouring services with an ESN.

Our qualitative data indicates the large variety of problems that underlie the need to access services between appointments. This variation would indicate that in future research, rather than selecting single outcome measures such as seizure frequency, measures that objectively assess how well different problems were addressed are required (see also[21]). A limitation of our research was that we only took carer report measures. Studies in which carer report is supplemented by audit of service contacts would establish both how frequent efforts to contact services between clinics were, and provide confirmatory reports of the type of presenting issue, and its resolution[21].

Finally, our results indicate the degree to which other professionals try to meet the needs of carers and patients when an ESN is not available, to avoid adverse effects to patients. This would suggest that the danger of burn-out may be higher in services without ESNs, something future studies should consider measuring, together with patient-focussed outcome measures.

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