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Right Time, Right Place: Mapping Service Provision for Babies, Children and Young People with Life-Limiting or Life-Threatening Conditions: A Point Prevalence Case Study

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Abstract

Background

This paper will share a primary study which explored needs and services for babies, children, young people experiencing life-limiting or life-threatening conditions at an acute visit as reported by healthcare professionals in the field from two regions of England.

Methods

This mixed methods evaluation combined Phase 1; A rapid review, Phase 2; Semi structured interviews of healthcare professionals (n = 10) and Phase 3; An electronic survey employing a case study point prevalence approach following an acute visit (n = 81). Framework analysis was conducted on the qualitative data (Phases 2 and 3 respectively) and the themes, codes and categories triangulated and presented collectively. Quantitative survey data was analysed using Chi-square test and independents t tests on SPSS IBM V29 and descriptive statistics obtained.

Results

No literature relevant to the assessment of needs in this population was identified by the rapid review and is reported elsewhere [1]. Significant inter - regional inequalities in the availability of 24/7 end of life medical and nursing care was revealed. *S*ervices functioned well where expertise and leadership matched population needs.

Conclusions

An important primary project sharing innovative findings which highlighted inter and intra-regional inequities in the access and available provision of key palliative care services required by babies, children, and young people with life-limiting or life-threatening conditions and their families in two large, diverse regions of England, United Kingdom. To resolve inequities in service provision leadership and training of multi professional team members in specialist competencies is recommended.

WHAT IS ALREADY KNOWN ON THIS TOPIC

Babies, children, and young people with life-limiting or life-threatening conditions and their families living in the community experience fragmented and inadequate service provision. However specific, information on their met and unmet needs and inter regional variation in service provision in the United Kingdom is limited.

WHAT THIS STUDY ADDS

An important primary project sharing innovative findings to demonstrate inter and intra-regional inequities in the access and availability provision of key palliative care services required by babies, children, and young people with life-limiting or life-threatening conditions and their families in two regions of England, United Kingdom. Our study found that babies, children and young people's health needs are highly specialised and that a Multi-Disciplinary Team with clear leadership is needed to ensure consistent support in the community.

HOW THIS STUDY MIGHT AFFECT RESEARCH PRACTICE OR POLICY

There is an urgent need to undertake research to facilitate equitable and efficient resource allocation of palliative care services to this population in the United Kingdom. Revisions to training initiatives, regional leadership, and increased dual leadership may improve the co-ordination of care delivered to babies, children, and young people with life-limiting or life-threatening conditions and their families living in the community. Further integration of specialist competencies into curriculum training is recommended.

BACKGROUND

Babies, children, and young people with life limiting and life-threatening conditions experience one of three death trajectories. First progressive conditions which are fatal (e.g., spinal muscular atrophy), second conditions associated with limited life spans (e.g., cystic fibrosis) or third conditions that present on-going threat to life [1]). Due to improvements in medical technology, care, and treatments their survival and life spans have been extended [2–5]. Consequently, the prevalence of this population has increased internationally [3,6,7,8,]. Based on Fraser et al. (3) and current population estimates by UNICEF (9) this is 96504 babies, children, and young people in England approximately 1% of the population of babies, children and young people. This number is projected to increase up to 120,990 by 2030 [3, 10]

All conditions or symptom constellations are chronic, limit mental and or physical functional abilities [11] and reduce quality of life. Additionally in complex cases multiple body systems are affected, or they require life sustaining medical technology for vital body functions [11]. Despite this seriousness most babies, children, and young people experiencing life-limiting or life-threatening conditions, and their families live at home in the community being cared for by family and professional carers [5, 12, 13]. Therefore, efficacious care from mobile and responsive multi-disciplinary teams is required.

Specialist health services are organised according to the single-disease concept [14] meaning people who experience multiple needs are prone to experiencing healthcare fragmentation. Indeed, the national literature documents that existing health care models and services do not meet the intensive care needs of this population [15–18]. For example, only a third of local areas in England are currently able to meet the required standard for 24/7 end of life home care for babies, children and young people [1]. Ultimately this leads to, morbidity suffering and premature mortality. Facilitating improvements to support improved care coordination to meet needs equitably is both ethical and moral. Further, managing care effectively in community settings is a current goal from the National Health Service 2023/4 priority list [19] and the redesign of services for children a key priority under the National Health Service Long Term

Plan [20]. To develop integrated care models that are equitable and suitably staffed to meet their care and service requirements at the right time and in the right place an understanding of the current landscape of care provision and the paediatric population is required.

Currently, while there are widely accepted care-pathway frameworks and standards [21–23] there is no standardised method to assess care service needs for this population within community settings [1, 18]. Therefore, this study sought to assess the needs of babies, children, and young people experiencing life-limiting or life-threatening conditions and their families and availability of services across two regions of England, United Kingdom (UK). Further to understand service leadership undertaken by healthcare professionals and their training needs. A point prevalence case study approach to capture a real-world picture of the provision of care and service needs following an acute visit by the health professional was utilised. We aimed to explore how care needs were met (*what services look like*) and what could be better (*what they could look like to make it better*) to support care by the *right team, in the right place.*

METHODS

Design

A primary research project using a mixed methods approach comprising three phases according to the protocol (See Supplementary file one) was used. Phase 1; A rapid review, Phase 2; Semi structure interviews with healthcare professionals and Phase 3: A quantitative survey employing a point prevalence case study approach following an acute visit of a key healthcare professional. Five sites across two regions (Region one and two) of England, UK were identified at a single designated time point following the acute visit.

Ethical approval

was gained from the Research Ethics Committee at the Faculty of Medical and Health Sciences at the University of Nottingham Reference number FMHS 12–0422.

Patient and Public Involvement

A sample of three parents / carers and five healthcare professionals (independent to the study) from across both regions were consulted prior to the study commencing and sense checked findings as they developed.

Study Participants

Purposive sampling was used. The eligibility criteria for Phases 2 and 3 was being a healthcare professional (Registered Nurses, Medical Doctors, and/or Physiotherapists) from one of two regions in England, UK who were delivering services as part of their normal service paediatric palliative care plan.

Region one, included babies, children and young people with life-limiting or life-threatening diagnoses and a palliative care plan. Region two included babies, children and young people with severe neurodisability and persistent or recurrent acute life-threatening respiratory disease. The professional role of the 10 healthcare professionals (five from each region) who participated in the semi structured interviews is available in Supplementary file two.

Measures

Tools included a semi-structured interview (Supplementary file three) and/or a 54-item online closed survey (Supplementary file four), to allow exploration of caring for babies, children, and young people with life-limiting or life-threatening conditions and their families. Both were developed in consultation with families and healthcare professionals as part of patient and public involvement.

At the semi-structured interviews participants were asked to use case studies from their work to explore the existing care and services being delivered as part of the carer networks. The online survey comprised 18 open ended free text response questions, 36 closed questions comprising drop-down lists in a case study approach. All questions in Phase 2 and 17 questions in Phase 3 were optional and both qualitative and quantitative data was yielded.

Procedures

An agreed local paediatric medical or nurse consultant lead in each region approached healthcare professionals and provided information about the study. Eligible healthcare professionals who responded to the study could participate in either a semi-structured interview and/or the online survey. Following consent, a member of the research team at the University of Nottingham sent an email inviting participation to either the online survey and/or semi structured interview. For Phase 2, an agreed interview time was scheduled with consenting participants and captured real life situations in caring for the babies, children, and young people with life-limiting or life-threatening conditions and their families.

The sampling method was opportunistic with the first five consenting participants who met the inclusion criteria from each region interviewed. This sampling strategy was relevant to the research question, had the potential to generate believable explanations and enabled the generation of rich information and was feasible [24]. The Phase 3 survey was open between September 1st 2023 and 1st March 2023 which consenting participants could access on an IPAD provided by the research team. Immediately after an acute visit the consenting healthcare professionals provided anonymous case details for up the three babies, children, and young people experiencing life-limiting or life-threatening conditions. No, changes to care or interventions were implemented.

Data Analysis

The Phase 2 qualitative interview data was analysed using framework analysis (SCF; JC) whilst Phase 3 survey data were entered into Microsoft® *Excel* and SPSS IBM V29. No imputation or adjustment was undertaken for missing data. The qualitative data from free response questions in the survey were analysed sequentially using inductive content analysis and descriptive statistics (ST; JC). The themes, codes and categories were then triangulated and are collectively presented here. The study is reported according to Symonds and Tang (25).

RESULTS

Demographic, Familial, Care Setting Characteristics, and Hospital Requirements of the Babies, Children, and Young People with Life-Limiting or Life-Threatening Conditions

Of the 81 cases in Phase 3, 41 (51%) cases were located in region one and 40 (49%) were from region two. At baseline 34/74 (51%) required Specialist, Acute or High Dependency care. Most cases were in the 5-year-old to 11-year-old age group 31/81 (38%), largely male 53/81 (65%), and White British 59/81 (73%). Chi square revealed no significant difference between both regions for any demographic variable ($p > 0.05$). 'Natural' parents cared for all babies, children, and young people with life-limiting or life-threatening conditions and most lived with two parents 62/81(76%) being cared for in the home 72/81(89%).

Family homes were described as having become like an extension of an acute hospital. Moreover, four families needed to use intensive technology and/or specialist equipment with rooms in the home such as bedrooms reflecting this. This represented a heavy caregiver / parental burden as illustrated in the following quote:

"When *we aren't there, families don't stop. They are clinical 24/7." (Participant 2, Phase 2)*

Healthcare professionals considered their role to be important in supporting care giving and for babies, children, and young people with life-limiting or life-threatening conditions to remain at home with their families. Despite the low use of hospice and acute ward settings, the support provided to families and healthcare professionals was perceived as vital. For example,

"Without carers, the child's care would be unmanageable at home and due to a breakdown in this care package, the child has been in hospital for 12 months." (Participant 8, Phase 2).

When acute hospital care was required both local and regional hospitals were required. For example, "*Local district general hospital paediatric ward - high dependency.*" (*Participant 7, Phase 3*). However, the ability to support the case is a paramount factor so both wards and staffing must be suitable for patient needs. For example: *"Specialist team in underlying condition based here."* (*Participant 4, Phase 3*).

Clinical Characteristics of the Babies, Children, and Young People with Life-Limiting or Life-Threatening Conditions

The most frequent diagnosis in the cases studied were congenital conditions 34 (42%), nervous system 28/81 (35%), perinatal 20/81 (25%), respiratory 14/81 (17%), and endocrine 10/81 (12%). Twenty-nine (36%) of babies, children, and young people experienced more than one primary condition. Further 30 (37%) experienced a secondary diagnosis most frequently affecting the nervous system 19/30 (63%), respiratory system 14/30 (47%) or of congenital origin 8/30 (27%). All other primary and secondary diagnoses were experienced by five or fewer cases. Chi square tests revealed no statistically significant difference between the two regions ($p > 0.05$) in primary diagnosis.

Care and Services provided to Babies, Children, and Young People with Life-Limiting or Life-Threatening Conditions

In 74/81 (91%) of cases across both regions the service provider was the National Health Service. The care provided was mostly clinical care services in 74/81 (91%) but also included assessment of needs in 55/81 (68%), and co-ordination in 33/81 (41%). Only 24/81 (30%) had access to non-medical care services such as or psychological care 16/81, spiritual care 15/81 (18%), or social care 12/81 (15%) and in 22 of these cases was available only in region 2. The difference by region in care services is shown in Fig. 1. All other care services were offered in fewer than five cases. The relation between region and offering of assessment of needs was statistically significant X^2 (4, N = 81) = 1.22, $p < 0.001$) with a high power achieved (> 0.90). Almost all 39/40 (98%) of babies, children, and young people in region two were offered this service compared to 16/41(39%) in region one.

Figure 1

Care Service Type Utilisation by Region

Reasons for the Acute Visit

Symptom management was the commonest reason for visit required by 54/79 (68%) of the babies, children, and young people, followed by assessment 27/79 (34%) and procedure 19/79 (24%). Inter-regional variations in service requirements were evident (See Fig. 2). The relation between region and requirement for assessment of needs was statistically significant X^2 (4, N = 79) = 1.11, $p < 0.001$) (2 (5%) Region 1 vs. 27 (68%) Region 2) with a high power achieved (> 0.90).

Figure 2

Reasons for the Selected Acute Visit by Region

Regional Disparity in Service Availability at the Acute Visit

Twenty-nine different services were required at the visit. However, 25 services (86%) were required by four or fewer cases. Participants required a mean of 1.72 services (SD = 1.44), with the number of services ranging from 1 to 9. There was a statistically significant difference between regions (U = 1135, p = 0.001) (1.37 Region 1 and 2.13 Region 2) in average service requirement with a power of 0.75.

Service need was centred on four services Respiratory Physiotherapy 44 (55%), Community Children's Nursing 28 (35%), Palliative Nursing 21 (26%) and Palliative Medical 9 (11%) accounting for 72% of the needs. However, as shown in Fig. 3 this need differed by region.

Figure 3

Services Required at the Acute Visit by Region

Twenty-nine (36%) of babies, children and young people had access to both palliative care and respiratory physiotherapy with most being in region 2 (18/29 (62%)). Twenty-nine (36%) had access to respiratory physiotherapies only and 19 (21%) palliative care only. In three (4%) cases neither speciality was available. Yet need for both is illustrated in the quote below.

"Access to support from a specialist paediatric palliative care service as the child's condition is life limiting and there has recently been a deterioration in his clinical presentation." (Participant 11, Phase 2).

Further the benefits of rapid response were supported in 14/40 (35%) cases to highlight that the service had prevented hospital admissions.

Overall, in region 1, 45/55 82% of needs were met and 66/86 77% in region 2. However, 20/80 (24%) cases did not have all their needs met at the visit with 30 (21%) out of 141 services required not being available. This represented a total of 21 (72%) services including essential palliative care services. These were palliative nursing team (4), physiotherapy (4), dietician (2), pain management (2), 24-hour service provision (2), Abeena continence service, body physiotherapy, cardiology consultant / liaison services, child development team, educational provision, specialist epilepsy nurse, general practitioner, hospital admission, learning disability team, occupational therapy, paediatric respiratory consultant, palliative medical, play therapy, seizure management, social care, and specialist nurse all one. Two cases had none of their required needs met and six had 50% or fewer of their needs met. Qualitative data supported this with 22/52 (42%) healthcare professionals stating the requirement for additional services.

Overall, 40 different services were available at the visit with a range of 1–19 (See Table 1). The mean number of available services was 9.33 (SD = 3.70). However, many of these services were not utilised, resulting in a mean surplus of 7.93 services (SD = 3.85), with surplus values ranging from 0 to 18.

Table 1

Services Available at the Acute Visit

Number	Service	Total Number Available	Region 1	Region 2
1	Community Children's Nursing	73	34	39
2	General Practitioner	57	31	26
3	Respiratory Physiotherapy	57	39	18
4	Body Physiotherapy	54	34	20
5	Occupational Therapy	53	26	27
6	Community Paediatrician	50	27	23
7	Education including Education – home schooled	43	23	20
8	Dietetics	42	23	19
9	Hospital Paediatrician Based at a Tertiary Centre	39	15	24
10	Palliative Nursing Team	37	11	26
11	Palliative Medical	36	7	29
12	Hospital Paediatrician Based at a District General Hospital	32	14	18
13	Speech Therapy	32	17	15
14	Pharmacy	24	10	14
15	Community Nursing	20	12	8
16	Play Therapy	13	1	12
17	Pain Management	10	3	7
18	24-hour Service Provision	10	1	9
19	Child Development Team	7	5	2
20	Learning Disability Team	7	3	4
21	Social Care	7	0	7
22	Non-Specialist Palliative Nursing	6	0	6
23	Chaplaincy	6	0	6
24	Podiatry	6	5	1
25	Counselling Services	4	2	2

Number	Service	Total Number Available	Region 1	Region 2
26	Audiology	3	2	1
27	Child and Adolescent Mental health team	2	1	1
28	Mental Health Services	2	2	0
29	Social Worker	2	0	2
30	Acorns Children's Hospice	1	0	1
31	Adult Respiratory Care	1	0	1
32	Continence Support from Continence Nurse Specialist	1	0	1
33	Day Centre	1	1	0
34	Hydrotherapy	1	0	1
35	Interpreter Services	1	1	0
36	Long Term Ventilation nurses / physio	1	1	0
37	Neuropsychiatry	1	1	0
38	Psychiatry	1	0	1
39	Respiratory / Long Term Ventilation Consultant Team	1	1	0
40	Social Services from Adults as no Paediatric Service	1	0	1
Total 745 353 392				
Miscellaneous				
41	Eligible for continence service referral but not available in area	0	0	1

Time requirements for visits were identified as a key challenge. The mean visit duration was 112.05 minutes, with visit lengths ranging from 20 minutes to over 23 hours. Additionally, 51 of 81 respondents (63%) reported requiring flexible visit scheduling. This is with current specialist staffing availability challenging in line with the extract below.

“We have a nurse consultant, Consultant and Doctor who would be able to review the child but we can not necessarily drop and run immediately depending on where we are at the time.” (Participant 17, Phase 3).

As documented in Table 2 Chi square analysis revealed statistically significant differences in availability of key palliative services between regions. This was supported by the effect sizes showing at least a

weak positive association between regions and the availability of the service. The largest inequity was in accessibility to 24/7 End of Life Medical and Nursing Care with 100% availability in region one and 30% availability in region two with a high power achieved (< 0.90).

Table 2
Availability of Key Palliative Care Services by Region

Region			
Service	**Region 1 n = 40**	**Region 2 n = 40**	**χ2**
24/7 end of life medical and nursing care	12 (30%)	40 (100%)	X^2 (1, N = 80) = 43.07, p < 0.001 Φ =-0.580
Rapid response physiotherapy	37 (93%)	13 (33%)	X^2 (1, N = 80) = 25.81, p < 0.001 Φ = 0.734
Palliative medical care	7 (18%)	29 (73%)	X^2 (1, N = 80) = 24.44, p < 0.001 Φ = -0.620
Palliative nursing care	11 (27.5%)	26 (65%)	X^2 (1, N = 80) = 11.31, p < 0.001 Φ = 0.553
Respiratory physiotherapy	39 (98%)	18 (45%)	X^2 (1, N = 80) = 30.72, p < 0.001 Φ = 0.376

Regional Differences in Leadership and Training Provision

Thiry nine (48%) (21 from region 1 and 18 from region 2) participants detailed additional qualifications. The most frequent was respiratory training 20 (51%) independent prescribing 17 (44%) and palliative care 12 (31%).

Eighty (99%) participants named a service lead the most frequent in this sample being palliative consultant 25/79 (32%), physiotherapist 20/79 (25%), palliative care nurses and family services 10/79 (12%). In nine (11%) cases there was dual leadership with six examples of a palliative consultant and a palliative nurse sharing leadership in region two and three cases of dual leadership in region one between a palliative care consultant and an extended scope practitioner (two in respiratory physiotherapy). Leadership matched regional strengths in terms of speciality.

DISCUSSION

This is a significant study in terms of showing inter-regional inequities in access to 24/7 End of Life medical and nursing care, palliative care, and respiratory physiotherapy. However, variation intra-regionally was also evident specifically in terms of access and availability. For example, some babies, children, and young people in both regions had access to both palliative care and respiratory physiotherapy. This variability is consistent with previous national and international work [12, 15, 18, 26, 27]. The perilous nature of services was supported by qualitative data and consistent with [1, 16, 18, 26, 28]. Interestingly the data set showed that availability of palliative care and respiratory physiotherapy mapped to focussed leadership and additional training opportunities. Despite the overall need for multi-disciplinary care evident from the range of diagnoses need at an acute visit is specialised.

While more research does need to be undertaken insights gained from this study can inform efforts internationally that embrace the philosophy of paediatric palliative in two ways consistently advocated for in the literature [26]. One to improve the coordination of services and second continuing care packages to support equitable outcomes for this population.

Outside of an acute visit the data from this evaluation and the literature documents this populations needs are wide ranging [3, 15, 18, 29]. Therefore, we support recommendations by [30–32] for the provision of multi-disciplinary 24/7 integrated care and local authorities (including social care and education) under clear clinical expert leadership. Specifically, we suggest improvements to the communication networks of health care professionals, across and between community and acute/tertiary services and between disciplines across regions. Also to consider the integration of care services including documentation such as needs assessment and escalation plans across regions. This we argue could facilitate equity in service provision between and within regions minimizing missed opportunities for support. The ultimate aim would be seamless and coordinated care where every contact counts towards reducing risk of acute need and preventing hospitalisation.

To support care by the *right team, in the right place* it is recommended that there is regional sharing of human resources knowledge, medical and technological resources, more partnership formed across, and between the regions for training and professional development, and as recommended by Together for Short Lives (18) single point of access care. Such sharing can support flexible sharing of skills to support skill diversity both regionally and nationally. To support this, mapping of current regionally provided healthcare professional training is required to identify opportunities for shared learning to apply to national service care and delivery is required. Further we advocate, for dual leadership to both upskill, share expertise, prevent domination of the perspective of one discipline, to support holistic care, and ensure expertise outside of palliative care and respiratory physiotherapy is available. Critically investment is needed in medical consultants, registered nurses, and specialist practitioners.

Palliative care is a human right that reduces symptom burden and improves quality of life [33] and the International Children's Palliative Care Network (34) advocates for its use from diagnosis. Additionally in the UK both palliative care and respiratory physiotherapy are recommended by NICE (21) for this population. Therefore, gaps in palliative care and respiratory physiotherapy service provision identified

here require urgent attention. As advocated by Hillier and Wee (35) all healthcare professionals require some education in palliative care and additionally respiratory physiotherapy. Practice must not be in line with the discipline or perspective but based on clinical need which may vary along the illness trajectory.

Importantly as advocated by Bogetz et al. (36) there must be a move away from predominantly crisis-driven management for children with medical complexity to one that emphasizes anticipatory and contingency care planning. Research using artificial intelligence and mobile health technology is developing for predicting adverse outcomes in emergency departments [37] and in the community [38]. Such research on babies, children, and young people who experience life limiting and life-threatening conditions could provide valuable data to both predict acute episodes, identify risk factors, and points of intervention to prevent acute episodes from occurring.

The characteristics of the sample are consistent with data from the UK reported by Fraser et al. Jarvis et al. Fraser et al (3, 4, 39). For example, most cases were male and congenital and nervous system conditions were the two most prevalent conditions experienced. Meanwhile the age range was fitting of a community sample and of trends from Fraser et al. (3). Also, the predominance of single diagnoses is consistent with Fraser et al (3): multiple diagnosis being associated with age as per Jarvis et al. (4). The ethnic composition of the sample is consistent with Jarvis et al. and the age group represented.

The study takes steps toward assessing need and highlights an example of regional disparity in the UK. The solutions suggested maybe applicable beyond the two regions to elsewhere in the UK and international healthcare contexts. However, the survey sample size whilst of sufficient power was relatively small (81 cases) and further work on a larger sample is needed to gain more accurate population level estimates of service inequity. The data was collected over a relatively short time frame with some unknown and missing data prevented a full understanding of the full experience of this sample. Despite the limitations cited, the project has provided a unique lens, via healthcare professionals, on service needs of babies, children, young people with life-limiting or life-threatening conditions and their families.

CONCLUSION

This was a significant, original study using an in-depth, novel case study approach exploring the availability of key palliative care services required by babies, children, and young people experiencing life-limiting or life-threatening conditions and their families in two regions of England, UK. New insights were illuminated about the coordination of community care of which further research is required to fully understand. To support equity of outcomes and improved capability an integrated, multi-disciplinary approach delivering insights into the *right team* in the *right place* at the *right time* is recommended. Further the need for improved use of efficient resources including regional training and co-ordinated leadership is underlined.

Declarations

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Authors' Contributions

JC was the lead for the evaluation; editing of the manuscript; development of the project and questionnaire; coordinated and supervised the data collection; interpretation of the data. ST drafted the initial manuscript and reviewed and revised the manuscript; formulation of tables and figures; qualitative and quantitative data analysis and interpretation of the data. SCF data collection of qualitative data to inform the design of the questionnaire and qualitative data collection. SR reviewing the literature and editing of the manuscript. BK co lead for the evaluation and editing of the manuscript. CA co lead for the evaluation and editing of the manuscript. DW editing of the manuscript. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Disclaimer

All opinions expressed in this paper are strictly the authors. JC (acting

as the guarantor and is responsible for the overall content of this study) led the

design of this study, wrote the protocol and secured funding with CA.

SGF collected the data, and it was later analysed by SGF (qualitative Phase 2) ST (Phase 3) overseen by JC.

Competing Interests

The authors declare that they have no competing interests

Patient and Public Involvement

Patients and/or the public were involved in the

design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient Consent for Publication

Not applicable.

Ethics Approval and Consent to Participate

Ethical approval was obtained from the Research Ethics Committee of the Faculty of Medicine and Health Sciences at the University of Nottingham (FMHS 12-0422). The study was conducted in accordance with the ethical principles of the Declaration of Helsinki and its subsequent amendments. Informed consent was obtained from all adult healthcare professional participants prior to participation. No identifiable information relating to any child or young person under 18 years was obtained, collected, or recorded as part of this study. Any information provided by healthcare professionals related only to their professional experiences and was collected in a manner that maintained full confidentiality and anonymity.

In accordance with the UK Policy Framework for Health and Social Care Research [40] informed consent requirements apply to individuals who are research participants. As minors were not participants in this study and did not provide data directly, parental or legal guardian consent was not applicable. The study was conducted with appropriate ethical oversight and in accordance with relevant confidentiality and data protection requirements, including the principles outlined in the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018. Agreement to conduct the study was obtained from the Right Team / Right Place Steering Group and Together for Short Lives.

Provenance and Peer Review

Not commissioned, externally peer reviewed.

Clinical Trial Number: Not applicable.

Availability of Data and Materials

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Supplementary Material

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Figures

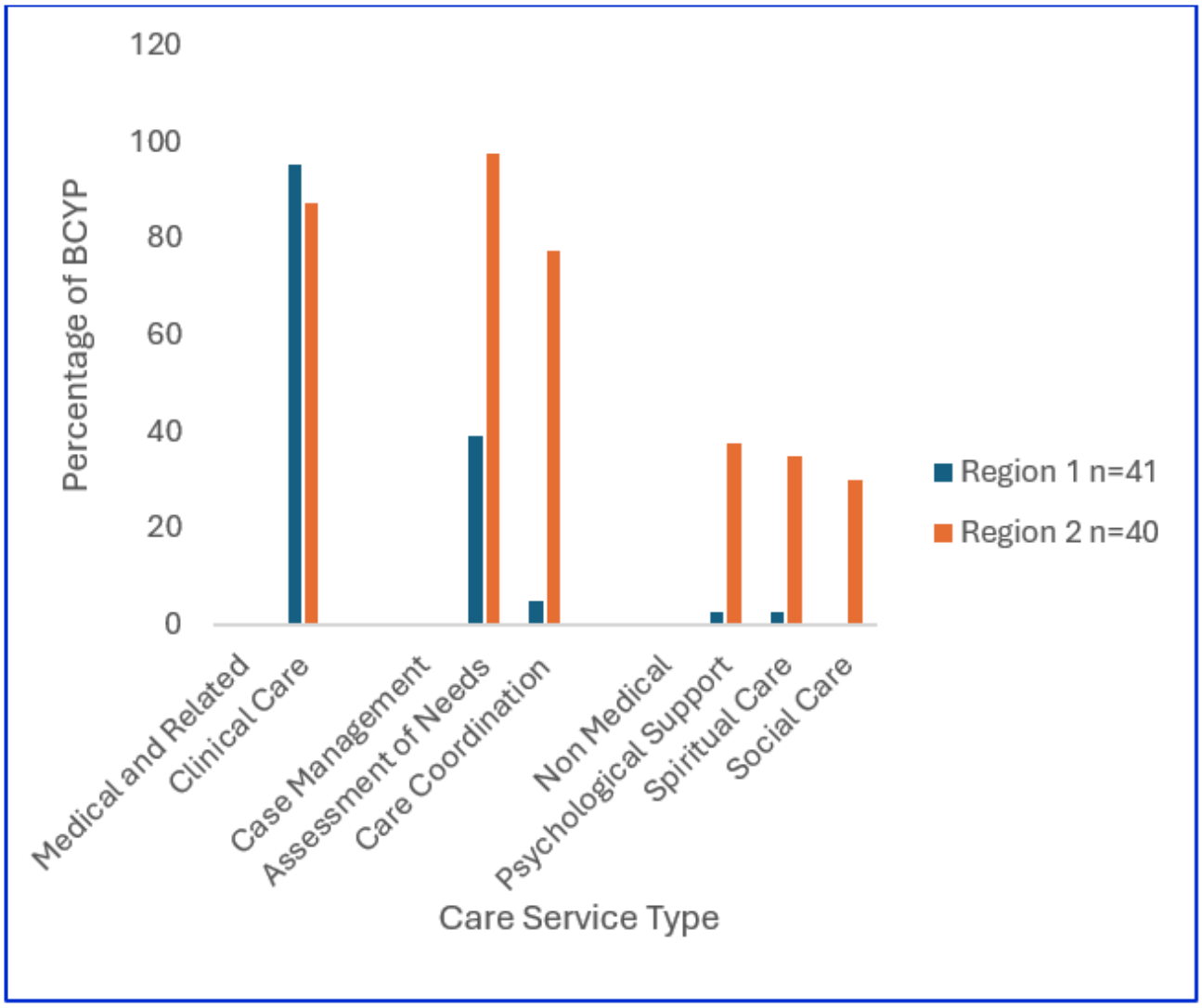


Figure 1

Care Service Type Utilisation by Region

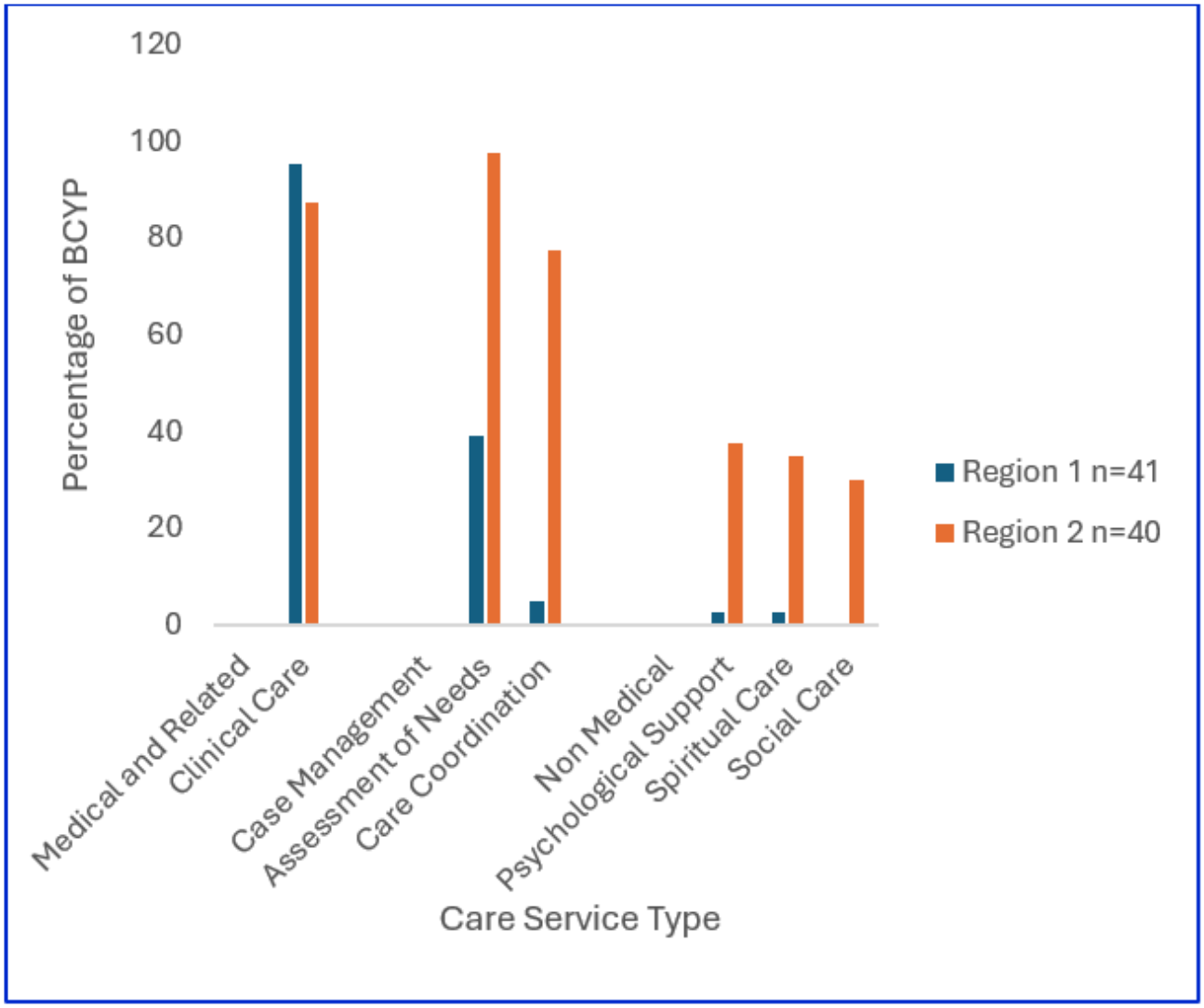


Figure 1

Care Service Type Utilisation by Region

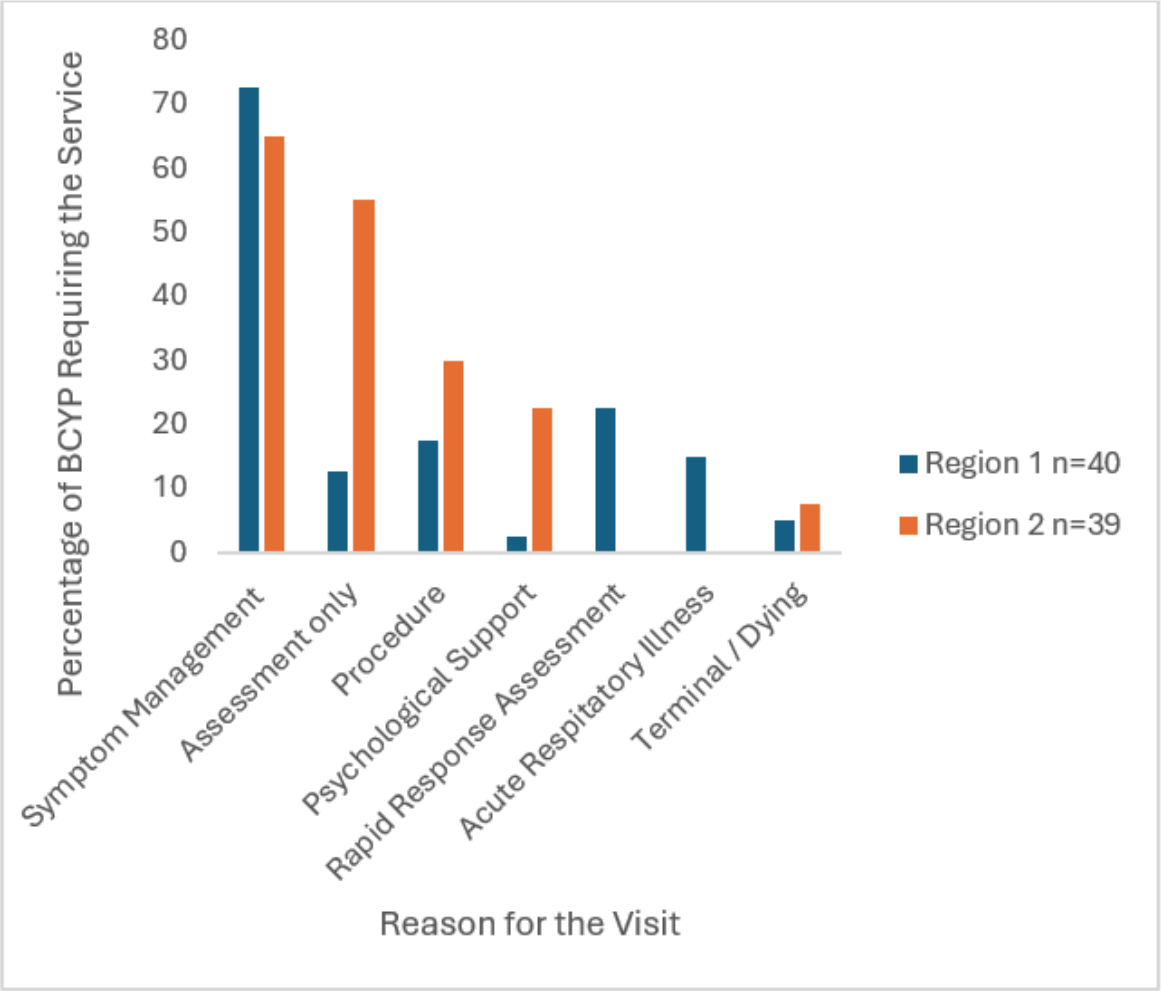


Figure 2

Reasons for the Selected Acute Visit by Region

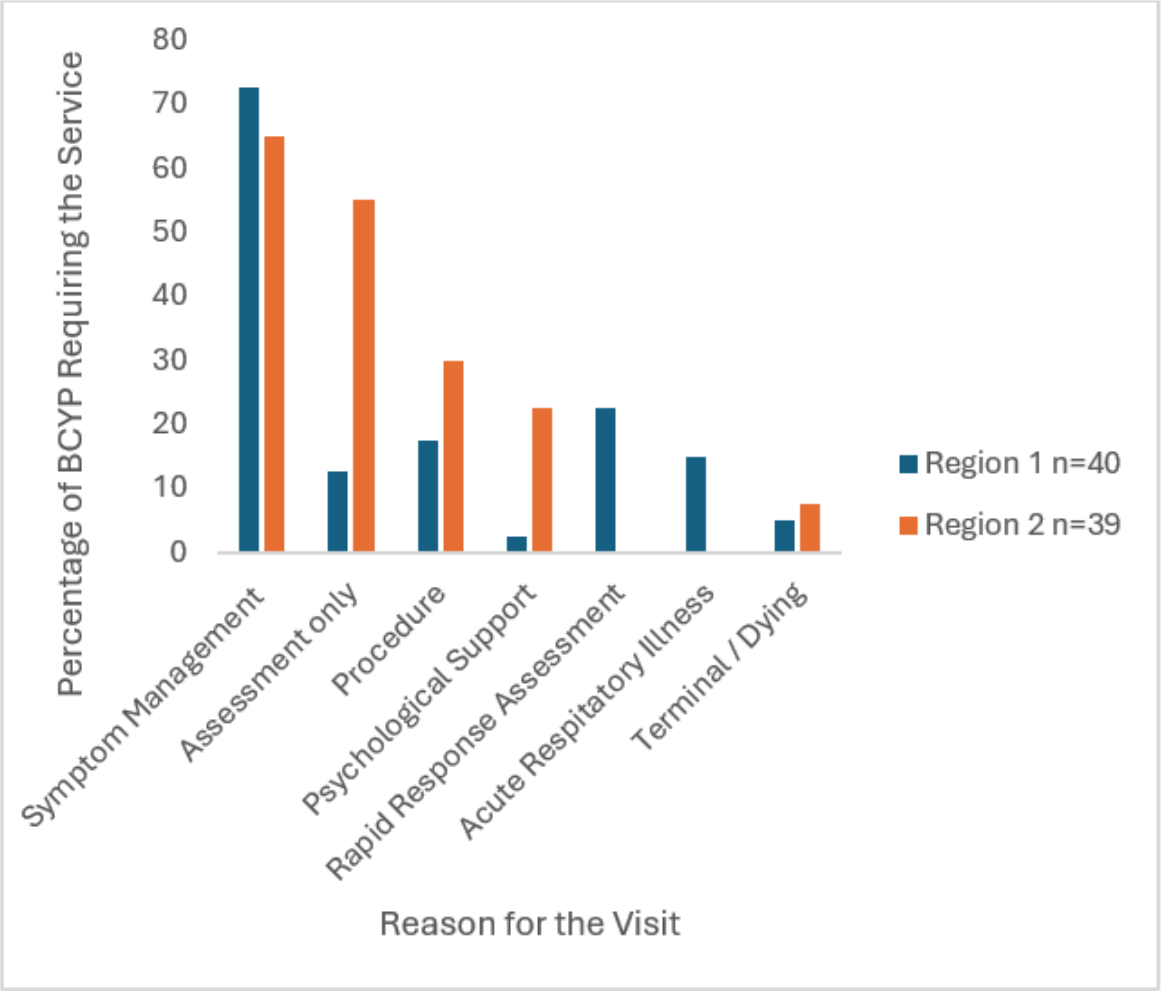


Figure 2

Reasons for the Selected Acute Visit by Region

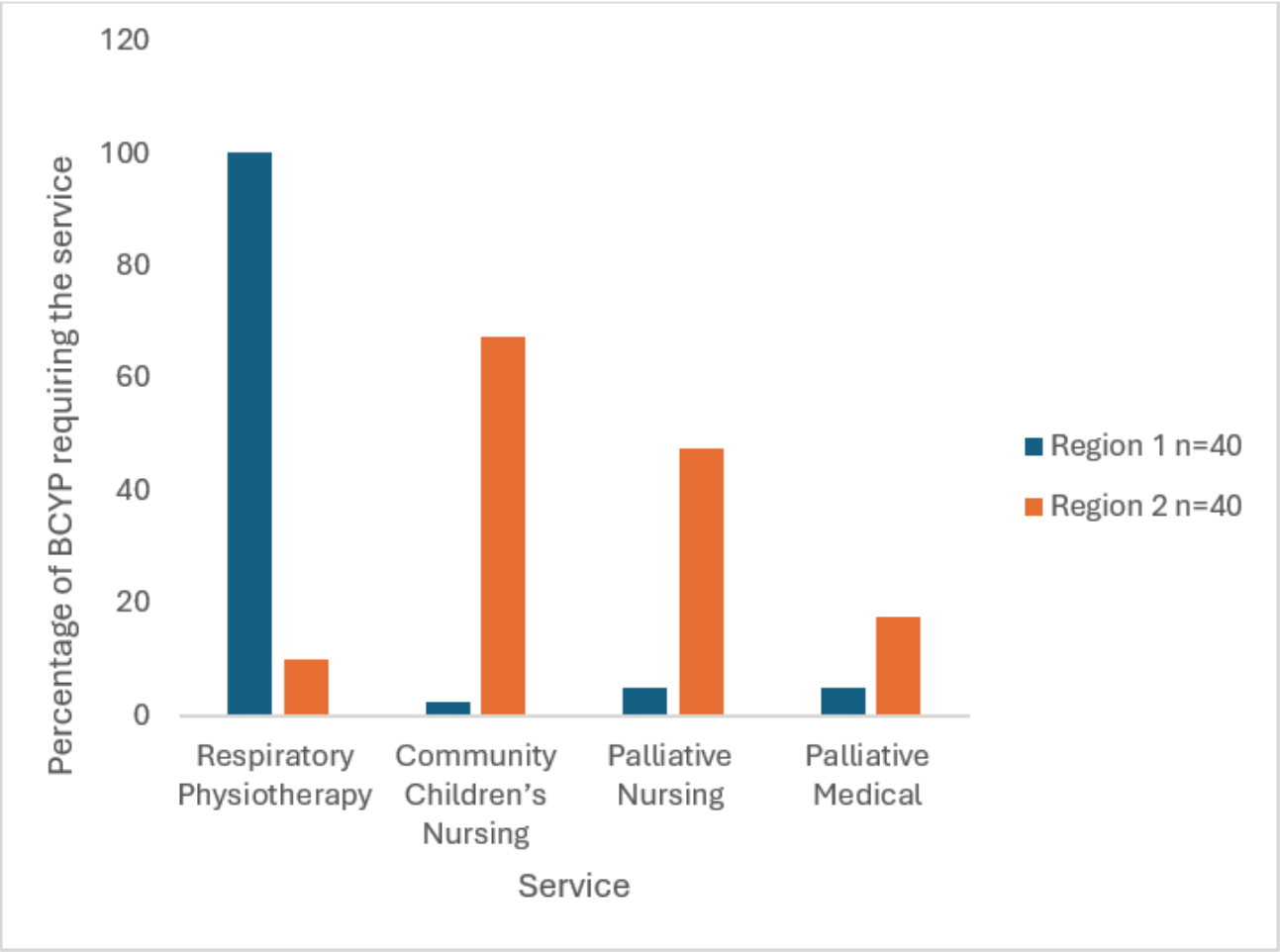


Figure 3

Services Required at the Acute Visit by Region

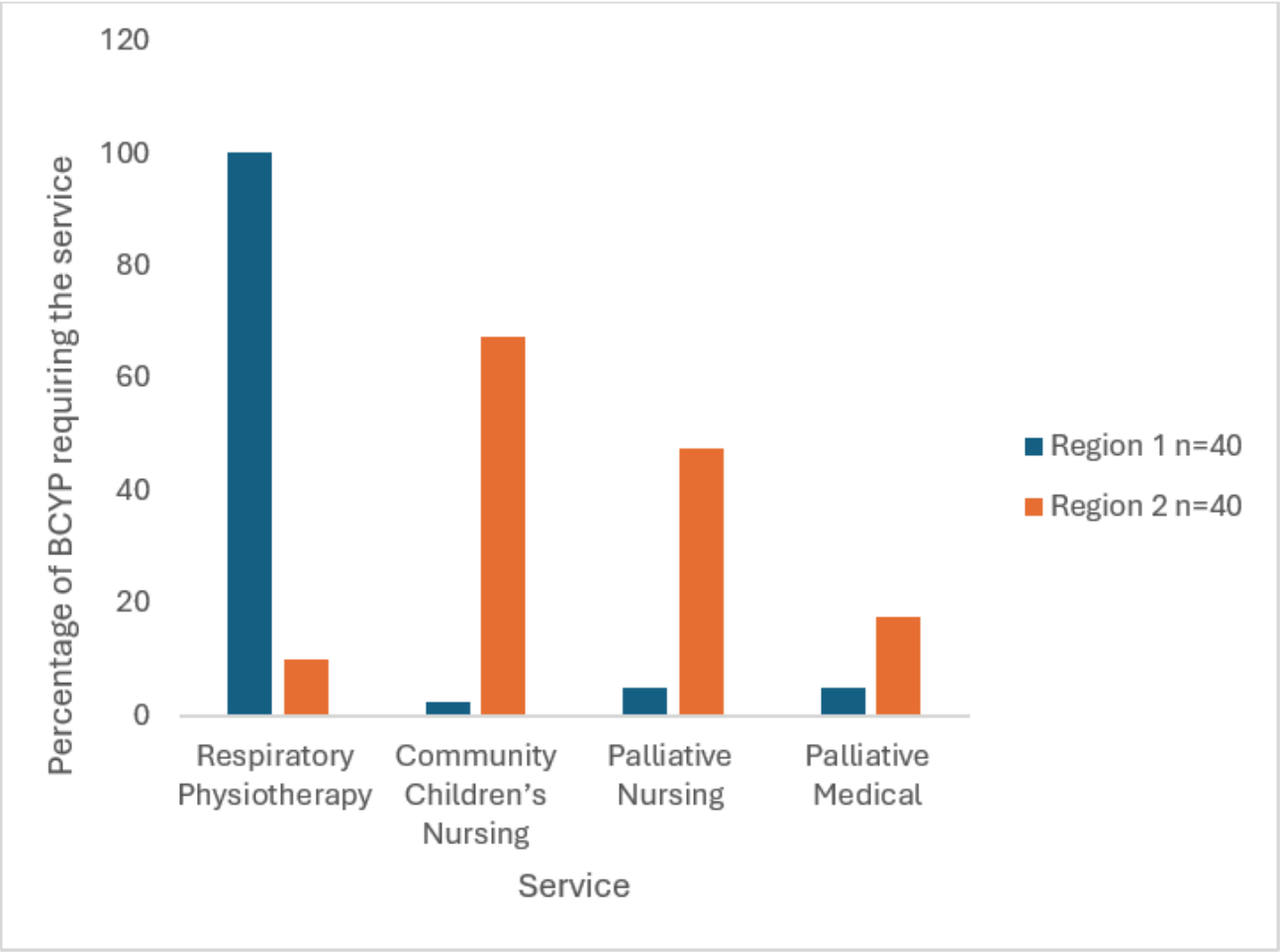


Figure 3

Services Required at the Acute Visit by Region

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