

## GPs and paediatric oncology palliative care: a Q methodological study

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**TITLE**

GPs and paediatric oncology palliative care: A Q Methodological study.

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## **ABSTRACT**

### **Objective**

This mixed methods study set in the West Midlands region of the United Kingdom demonstrates the effectiveness of Q methodology in examining general practitioners' (GPs') perception of their role in children's oncology palliative care.

### **Methods**

Using data obtained from the analysis of semi-structured interviews with GPs who had cared for a child receiving palliative care at home and bereaved parents, 50 statements were identified as representative of the analysis findings. 32 GPs with a non-palliative child with cancer on their caseload were asked to rank the statements according to their level of agreement/disagreement on a grid. They were then asked to reflect and comment on the statements they most and least agreed with.

The data were analysed using a dedicated statistical software package for Q analysis PQMethod 2.20 (Schmolck 2012). A centroid factor analysis was undertaken initially with 7 factors then repeated for factors 1-6. Varimax and manual flagging was then completed.

### **Results**

Four shared viewpoints were identified denoting different GP roles: The General Practitioner, The Compassionate Practitioner, The Team Player Practitioner and The Pragmatic Practitioner. In addition consensus (time pressures, knowledge deficits, emotional toll) and disagreement (psychological support, role, experiential learning, prior relationships) between the viewpoints were identified and examined.

### **Conclusions**

Q methodology, used for the first time in this arena, identified four novel and distinct viewpoints reflecting a diverse range of GP perspectives. Appropriately timed and targeted GP education, training, support, in conjunction with collaborative multi-professional working, have the potential to inform their role and practice across specialities.

## **INTRODUCTION**

Although rare, cancer still causes the majority of deaths by disease in 0-19 year olds [1] accounting for more than 400 deaths a year in the United Kingdom (UK)[2]. Families' preferences for their child to die within the family home[2] highlight the importance of the GP's role.

GPs often have minimal contact with these families, in part due to the rarity of the condition but also because the child's first contact when unwell during treatment is the hospital[3]. The often short duration of palliative care (weeks to months) compared to other life-limiting conditions (which can be years)[4, 5], can also result in minimal opportunities for the GP to meet, and develop an effective working relationship, with the family. However, GPs recognise their role in paediatric palliative care (PPC) as important, acknowledging they can add value to the care provision and gain personally from the experience[3, 6, 7]. PPC is usually provided by a multi-professional team, which may comprise a specialist PPC consultant, specialist nurse, GP, community children's nurse and allied health professionals, such as physiotherapists[3]. Although most GPs use out-of-hours service providers there is a recognized lack of uniformity in out-of-hours PPC provision in the UK[8, 9]. The need to educate GPs in PPC is well recognised[10,11] with skills such as good communication seen as integral to exemplary palliative care[6, 10].

Studies examining experiences of PPC, from the perspectives of the bereaved parent and hospital doctor[6] and hospital paediatrician and family practitioner[11] exist, but no UK study has examined bereaved parent and GP perspectives of the GP's role in oncology PPC. Q methodology (QM) (a research method that clusters participants' experiences according to similar viewpoints) was identified as a method for statistically examining data from interviews with bereaved parents and their GPs.

## **METHODS**

This mixed methods study used semi-structured interviews, grounded theory analysis and QM to examine the role of the GP in oncology PPC. Ethical approval was gained from South Birmingham Research Ethics Committee (10/H1207/25).

### **Q methodology**

Developed in the 1930's [12, 13] QM systematically captures and examines shared subjective opinions and subjects these to rigorous statistical analysis: drawing insight from both qualitative and quantitative approaches. A strength of the method is that it can be combined with other data collection methods, such as interviewing. QM clusters participants' experiences according to similarity of viewpoint, producing a series of 'stories' that reflect the individuals' lived experience.

The process, called Q sorting, involves participants (P set) being presented with statements about the topic (Q set) and asked to rank-order according to their own viewpoint (usually from 'agree most' to 'agree least'): a modified rank ordering

procedure where participants typically place items on a specially created grid arranged along a 7, 9 or 11 item continuum. Each Q sort is then correlated and subjected to an exploratory factor analysis to identify operant factors, typically between 2 and 7, that are then interpreted as shared viewpoints. Q sorts can be administered online but most widely used as part of a face-to-face interview. QM is credited with being able to break down communication barriers often associated with conventional qualitative interviewing. The quality of QM research design rests on the ability of the researcher to create a Q set that samples the diversity of views surrounding the topic. To capture views for the Q set researchers often conduct interviews or undertake literature reviews. A full description of the method can be found in Watts and Stenner 2012[14].

QM has been used widely within health-based research with topics including chronic pain[15], doctor-patient relationships[16] and fatigue in adolescents with cancer[17]. Although also used in palliative care (in assessing learners[18] and end of life decision-making[19]), no references to use in GP PPC roles have been found. In this context QM is particularly useful: GPs with no previous oncology PPC experience examine the viewpoints of bereaved parents and associated GPs, potentially identifying different perspectives, connections or viewpoints that could inform practice.

## **Participants**

The participant group, GPs of a non-palliative child with cancer being treated at a regional childhood cancer centre (RCCC) in the West Midlands, UK, was selected to inform strategies to meet the needs of GPs facing this rare, often unique, experience. Working retrospectively through a chronological database, patients diagnosed 2011-2012, from each diagnostic group (leukaemia, solid tumour, neuro-oncology) were identified. Patients living outside the RCCC catchment area and those not receiving active first-line treatment were excluded. GPs of the remaining patients formed the sample (n=61).

Guidelines for Q study participant numbers vary: some state 40-60 works well[20] others suggest a number of participants fewer than statement numbers[14] or a minimum of 25 to ensure sufficient numbers of respondents inform each factor[21]. The Q study is unusual in that it should be judged by the representativeness of the Q set rather than numbers taking part[21]. The aim of the Q study is to explore different perspectives on a topic, there being only a limited number of distinct viewpoints on any given topic, therefore Q research is more concerned with how many viewpoints are operant rather than how many participants hold a particular viewpoint[22].

## **Procedure**

To develop the Q set semi-structured interviews were undertaken with 11 bereaved parents and 18 GPs. The bereaved parents (whose child was treated at the RCCC but died at home) and associated GPs were selected chronologically from the RCCC specialist nurses' caseload [23]. The interviews were digitally recorded, professionally transcribed verbatim and analysed using grounded theory[24, 25]. Five categories of data were identified; GP role, parent view of GP role, symptom management, regional/shared care centre and bereavement.

Through meticulously reading the data, fifty-six statements representing the five categories were identified. Careful crosschecking and refining ensured the statements truly represented the range of viewpoints identified resulted in fifty statements. These were edited to ensure clarity and improve readability (Table 1) and printed onto individual laminated cards.

**Table 1 Statements**

	Statement	Factor arrays			
		F1	F2	F3	F4
1	The GP is the person that families feel they can always go to	0	1	0	1
2	Doses and medications in PPC are familiar	-4	-6	-6	-3
3	There's a lot GPs can learn from people who are specialists in looking after children needing palliative care	1	-1	4	5
4	Macmillan nurses are a great help in advising GPs on medications / dosages 24 hours a day	-1	3	4	4
5	The GPs role in paediatric palliation is limited as the specialist team manage the care	-3	4	-3	1
6	GPs should keep a professional distance with families during palliative care	-3	-3	2	-2
7	GPs turn to their colleague for support	1	-1	1	0
8	It's easy to translate adult palliative care theory to PPC	-2	-5	-6	-6
9	The GPs role is to support the parents and make sure that they are coping	3	1	5	2
10	GPs manage their own support needs	0	0	0	-5
11	Time restraints prevent GPs from seeing the palliative child and their family once a week at home	-3	0	-2	6
12	The GP rather than the hospital paediatrician should certify the death when the child dies at home	2	-2	1	-1
13	Regular home visits during palliative care are not necessary as families can phone their GP if needed	-5	0	-2	-3
14	It is important that only one GP from the practice is involved in the care	-4	1	-1	-3
15	Keeping regular contact with the family after diagnosis makes the transition into palliative care easier for the GP	5	1	4	3

16	When a child becomes palliative it is not clear to GPs how to make contact with the family and how often to visit	-2	1	0	4
17	GPs only visit at home during palliative care when the child gets very poorly	-1	-2	0	-2
18	GPs should be more like Dr Finlay; “pops out to see the patient regularly and knows all their family members”	0	-4	0	-1
19	Palliative care is very time consuming	5	2	-1	2
20	With pressures on time within general practice it’s getting increasingly hard to do the job as it should be done	3	3	3	6
21	PPC is challenging for GPs but manageable with support from experts	1	2	6	2
22	Although important, time constraints make it difficult for the GP to spend more than half an hour with a family	0	0	1	5
23	PPC provides the opportunity for good old fashioned general practice where the GP can make a difference	6	0	-2	-2
24	GPs are professionals, if they come across something they don’t know about they have to look it up or ask	2	2	3	3
25	GPs shouldn’t be side-lined in the care provision as they will still be looking after the family in another 10 years	3	6	2	0
26	GPs recognise things they don’t know but don’t have time to find out about it	-2	-2	-4	0
27	There is no prior relationship with the child and family like you would have with elder patients when they become palliative	-1	-1	-2	-1
28	Current PPC training is sufficient	-2	-5	-5	-4
29	The pastoral role of the GP in palliative care is not as important as the clinical one	-6	-4	-5	-2
30	When talking to the child and family you have to think carefully about what words you use and how you say it	4	4	1	3
31	GPs should be happy to have a role in the care even if they play a small role and the big role played by nurses	2	0	0	1
32	Routine “hello how are you? “ visits during palliative care are not appropriate	-4	-1	-3	-1
33	GPs shy away from openly talking about death and dying with their patients and families	-1	-3	-1	-2
34	PPC is something that comes naturally to GPs	-3	-6	-4	-6
35	GPs need more information about bereavement services for families	-1	2	2	2
36	The child and family should be discussed at the quarterly palliative care meetings	2	5	6	-1
37	Updating on the principles of paediatric palliation would be	-2	-3	-2	-3

	a futile gesture as it is such a rare event				
38	GPs are generalists and should not be expected to undertake specialist training	-1	-2	-3	-4
39	It's a good learning experience, you can do all your reading but actually having a real case is different	1	2	-1	0
40	Palliative patients are always prioritised and GPs give them all the time they need	1	3	1	1
41	GPs can manage the provision of PPC, this is what they are trained to do	0	-3	-3	-5
42	The GP is one of the core people involved in the care in the final days	3	-4	1	4
43	GPs routinely contact families after someone has died	2	-1	3	0
44	The GPs role is to ensure the out of hours service is updated as things change	1	6	5	-1
45	It would be useful to learn more about how to raise and talk about death and dying with families	0	3	3	3
46	It's important to be straight talking with the families and not skip around sensitive things	6	-1	-1	1
47	Although GPs are used to death as a doctor, a child dying has more of a profound effect on them	4	5	2	1
48	Being involved in a child's palliative care is emotionally draining no matter who you are	4	4	2	2
49	GPs used to do bereavement visits but just can't do that anymore it's now more of just making a telephone call to the family	-5	-2	-1	0
50	Family members are asked to make an appointment to see their GP 2-3 weeks after the death	-6	1	-4	-4

Participating GPs (of a non-palliative child with cancer) were given 50 individual statement cards and an instruction sheet (Table 2).

### Table 2 Participant instruction sheet

<p><b>Look at each card</b></p> <p><b>Divide cards into 3 provisional ranking categories:</b></p> <p><b>Category 1</b> The statements you agree with or you feel are definitely important.</p> <p>Place these cards to your right hand side.</p>
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**Category 2** The statements you definitely disagree with or feel are unimportant.

Place these cards to your left hand side.

**Category 3** The statements you feel indifferent about or those you feel induce both positive and negative feelings depending on the context.

**Place these cards directly in front of you.**

**All statements need to be allocated a place in the distribution relative to one another:**

-6 those you least agree with                      +6 being those you most agree with

**A statement ranked negatively does not mean you disagree with it but that you probably agree with it slightly less than the ones ranked immediately above it and slightly more than those ranked below.**

Spread out Category 1 cards and identify the 2 you most agree with, place these on the chart in column +1. Continue with the next 2 statements you most agree with and so forth through the columns.

Do the same with category 2 cards, starting with the 2 you least agree with and place these in -6.

Finally rank the statements in category 3 in the remaining columns.

Participants were asked to arrange the cards into three piles (viewpoint agreed with, viewpoint disagreed with and a 'neutral' pile for little or no view held). Starting with their viewpoint agreed cards, participants were asked to place the two cards they most agreed with in the +6 column on a grid (Table 3), followed by the next two agreed with in the +5 column and so on. This procedure was repeated with the cards in the 'disagree' pile (with -6 being the two cards they agreed with least) finishing with those in their neutral pile.

**Table 3 Sorting grid**

Agree least						Agree most						
-6	-5	-4	-3	-2	-1	0	1	2	3	4	5	6


On completion the Q sort was photographed and participants asked to document reasons behind their +6 and -6 choices and, to validate the Q set, any identified missing perspectives in the statements.

### Analysis

Data were uploaded and analysed using a dedicated statistical software package for Q analysis PQMethod 2.20[26]. The 36 Q sorts were correlated (aiming to identify factors that represented shared viewpoints) and four factors extracted and rotated. Correlation of each Q sort was then merged to produce a single configuration, known as a factor array (Table 1), and factor analysis undertaken to identify the participants' Q sorts that load (have a similar or dissimilar viewpoint) significantly on a particular factor (Table 4).

**Table 4 Individual Q sorts that loaded on factors (X indicating a defining set)**

Q sort	Loading 1	Loading 2	Loading 3	Loading 4
1 36	0.6541X	0.0926	0.1023	0.3683
2 25	0.5054	0.1354	0.0941	0.4242
3 29	0.0474	0.3799	0.1869	0.6497
4 45	0.1696	0.0443	0.3454	0.5868X
5 28	0.3846	0.0568	0.5227	0.0278
6 42	0.2077	0.5533X	0.1438	0.2852
7 12	0.8445X	0.1155	0.3672	0.0335
8 42	0.0716	0.4863X	0.1896	0.1107
9 22	0.3755	0.4983	0.0798	0.4020

10 23	0.0489	0.4258	-0.1055	0.4913
11 14	0.6445X	0.2040	0.2136	0.3460
12 26	0.3545	0.3496	0.0093	0.3582
13 25	0.3545	0.3496	0.0093	0.3582
14 23	0.2992	0.2866	0.1517	0.3244
15 22	0.5267	0.1449	0.2523	0.5967
16 16	0.1898	0.3620	0.4395X	0.3481
17 26	0.2592	0.3150	0.6517X	0.3291
18 55	0.4274	0.2406	0.7057	0.0263
19 64	0.4988	0.0685	0.4180	0.2268
20 59	0.0706	0.3520	0.0801	0.5952X
21 60	0.5786X	0.0389	0.3037	0.1614
22 61	0.1137	0.7890X	0.2998	0.2487
23 47	0.4467	0.3234	0.2863	0.5633
24 48	0.3271	0.2670	0.3183	0.1452
25 41	0.3234	0.2371	0.2008	0.6931X
26 38	0.2535	0.4749X	0.0561	0.3529
27 54	0.5698	0.4826	0.2595	0.1042
28 40	0.5435	0.3210	0.4162	0.1956
29 57	0.3808X	-0.0341	0.2890	0.2659
30 49	0.5649X	0.3265	0.1784	0.2577
31 11	0.4817	0.4084	0.1247	0.1378
32 37	0.6422	0.4343	0.2439	0.0982

A centroid factor analysis undertaken to extract the factors was run initially using seven factors, the maximum extraction, followed by analysis for factors 1-6. Varimax and manual flagging was completed, flagging with a loading of 0.36 or above.

Four factor arrays were documented and interpreted as shared viewpoints (Table 5 provides an example of the process using a crib sheet).

**Table 5 Example of a factor array interpretation crib sheet**

<b>Items ranked at +6</b>
23 Paediatric palliative care provides the opportunity for good old fashioned general practice where the GP can make a difference (6)
46 It is important to be straight talking with GPs and not skip around sensitive things (6)
<b>Items ranked higher in Factor 1 array than other factor arrays</b>
7 GPs turn to their colleagues for support (1)
8 It's easy to translate adult palliative care theory to paediatric palliative care (-2)
10 GPs manage their own support needs (0)
12 The GP rather than the paediatrician should certify the death when the child dies at home (2)
15 Keeping regular contact with the family after diagnosis makes the transition into palliation easier for the GP (5)
18 GPs should be more like Dr Finlay: "pops out to see the patient regularly and knows all the family members" (0)
19 Palliative care is very time consuming (5)
23 Paediatric palliative care provides the opportunity for good old fashioned general practice where the GP can make a difference (6)
27 There is no prior relationship with the child and family like you would have with elder patients when they become palliative (-1)
28 Current paediatric palliative care training is sufficient (-2)
30 When talking to the child and family you should think carefully about what words you use and how you say it (4)
31 GPs should be happy to have a role in the care even if they play a small role and the big role is played by nurses (2)
33 GPs shy away from openly talking about death and dying with their patients and families (-1)
34 Paediatric palliative care is something that comes naturally to GPs (-3)
37 Updating on the principles of paediatric palliation would be a futile gesture as it is such a rare event (-2)
38 GPs are generalists and should not be expected to undertake specialist training (-1)
41 GPs can manage the provision of palliative care, this is what they are trained to do

(0)

46 It is important to be straight talking with families and not skip around sensitive things (6)

48 Being involved in a child's palliative care is emotionally draining no matter who you are (4)

**Items ranked lower in Factor 1 array than in other factor arrays**

1 The GP is the person that families can always go to (0)

4 Macmillan nurses are a great help in advising GPs on medication/dosages 24hrs/day (-1)

5 The GP's role in paediatric palliation is limited as the specialist team manage the care (-3)

6 GPs should keep a professional distance during palliative care (-3)

11 Time restraints prevent GPs from seeing the child and family once a week at home (-3)

13 Regular home visits during palliative care are not necessary as the family can phone their GP if needed (-5)

14 It's important that only one GP from the practice is involved in the care (-4)

16 When a child becomes palliative it is not clear to GPs how to make contact with the family and how often to visit (-2)

20 With pressures on time within general practice it's getting increasingly hard to do the job as it should be done (3)

21 Paediatric palliative care is challenging for GPs but manageable with support from experts (1)

22 Although important, time constraints make it difficult for the GP to spend more than half an hour with a family (0)

24 GPs are professional, if they come across something they don't know they look it up or ask (2)

29 The pastoral role of the GP is not as important as the clinical one (-6)

32 Routine "hello how are you?" visits during palliative care are not appropriate (-4)

35 GPs need more information about bereavement service for families (-1)

40 Palliative patients are always prioritised and GPs give them all the time they need (1)

45 It would be useful to learn more about how to raise and talk about death and dying with families (0)

49 GPs used to do bereavement visits but just can't do that anymore it's now more of just making a telephone call to the family (-5)

50 Family members are asked to make an appointment to see their GP 2-3 weeks after the death (-6)

**Items ranked at -6**

29 The pastoral role of the GP in palliative care is not as important as the clinical one (-6)

## **FINDINGS**

Sixty-one GPs were invited to participate with 32 (52%) completing the Q sort. GP representation across patient diagnostic groups was achieved (leukaemia:10, solid tumours:12, neuro-oncology:10). Non-participating GPs (four) cited time-pressures, 19 gave no reason and six were not contactable.

Distinct viewpoints illuminated four views of practitioner roles: general practitioner, compassionate practitioner, team-player practitioner and pragmatic practitioner.

### **Factor Interpretation**

There is an element of researcher subjectivity when interpreting factors due to the hermeneutic process of understanding individual factors and consensus statements and their interactions with, and relationship to, the arena generating the data: a researcher's understanding can illuminate and contextualise identified viewpoints. Each factor will be discussed in turn along with the significant distinguishing statements (those with a  $P < 0.01$ ). Viewpoint descriptions are based on the location of statements in the factor array, for example Statement 26 being placed at position +6 on the grid (most agreed with) is referenced as '(23:6)'. Where comparison is of interest, such as consensus across the viewpoints to Statement 23, the factor scores for all viewpoints are referenced, i.e. '(20:3,3,3,6)' (Table 1). The term 'GPs' represents the factor viewpoint, rather than implying a specific cohort of GPs (as the identified shared viewpoints relate to individual statements rather than a GP's whole Q sort).

### **Consensus**

Consensus was identified where each of the four viewpoints agreed (or least agreed) with a particular statement. All four viewpoints agreed time pressures affected efficacy of working (20:3,3,3,6), GPs addressed knowledge deficits (24:2,2,3,3) and everyone involved found PPC emotionally draining (48:4,4,2,2). Unfamiliarity of paediatric doses and medications was also a common view (2:-4,-6,-6-3) along with a common, albeit moderate, view on keeping up to date with PPC given the rarity in practice (37:-2,-3,-2,-3).

It is important to note that, whilst every effort is made to represent a diverse set of statements in the Q set, some statements will be placed indifferently by a particular set of respondents for whom the statement may have little or no resonance. It could be argued that if respondents were relatively indifferent to particular statements, these had no place in the Q set, however collective indifference can be as revealing as other forms of consensus. Examples of this include statements 7 (1,-1,1,0), 31 (2,0,0,1), 39 (1,2,-1,0) and 27 (-1-1-2-1).

Whilst there was some consensus across the four viewpoints, each has a distinctive character and will be described using GP reflections and interview quotes to contextualise findings.

### **Viewpoint 1: The General Practitioner: Good old-fashioned general practice**

GPs believed they played an important role and could make a difference to care provision (23:6). These distinguishing statements, along with highlighted time pressures and identified training needs (communication, medication and bereavement support services for families), differentiated viewpoint 1 from others. Although PPC was acknowledged as time-consuming (19:5), “Time consuming compared with most other aspects of our job” (GP26) it was not perceived as more pressing than other areas of work. This might be related to recognised benefits from initiating home visits, rather than visiting only on request (13:-5, 32:-4).

Equal value was placed on their pastoral, as well as clinical, role (29:-5), “Just being there can be a support” (GP26). Building a close rapport with the family (6:-3) was seen as important, “You should make it a priority to get to know the family if a diagnosis of cancer is made” (GP24). Regular family contact from diagnosis aided engagement at the transition to palliation (15:5) and having a named GP ensured “a familiar point of contact and allowed rapport to be built up during a difficult time” (GP48). The importance of good communication skills was recognised: being able to talk openly to families and not avoid difficult conversations (46:6) required careful thought of what, and how, information was communicated (30:4).

GPs had sufficient information about available bereavement services (35:-1) but disagreed whether bereavement visits were offered (49:-5): rather than asking the family to attend the surgery (50:-6) there was an implication that home bereavement visits were undertaken.

The emotional toll of providing PPC was recognised (47:4, 48:4). GPs managed their own support needs and also gained support from colleagues (7:1, 10:0).

### **Viewpoint 2: The Compassionate Practitioner: To be valued not side-lined**

The importance of playing a key role in the care is linked to the unique longevity of contact (25:6) “GPs shouldn’t be side-lined as (*we will*) still be looking after the family in 10 years” (GP38). GPs however did not see themselves as one of the core people in the final days (42:-4) (a distinguishing statement for this viewpoint) due to the involvement of specialist teams (5:4). “GPs can feel redundant in PPC as patients receive such excellent care from secondary care. Families are encouraged to liaise with secondary care if they have a problem and not primary care” (GP37).

The pastoral role (29:-4) and regularly updating the out-of-hours service (44:6) were recognised as important and awareness of the emotional toll (48:4), including the more profound effect from the death of a child (47:5), was evident.

PPC did not come naturally to these GPs (34:-6). Insufficient training (28:-5) made translation of adult to PPC theory difficult (8:-5), particularly managing unfamiliar medications and doses (2:-6). Despite rarity of experience, updates on the principles of PPC were perceived useful (37:-3).

**Factor 3: The Team-Player Practitioner: Has role clarity and welcomes specialist support.**

PPC was viewed as challenging but manageable with support from experts (21:6), suggesting a team approach. These GPs viewed their clinical role as more important than their pastoral role (29:-5), recognising their role in supporting parents (9:5) whilst maintaining professional distance (6:2). Their ability to identify and address learning deficits (24:3) suggests a level of self-confidence and role clarity.

PPC training was not perceived sufficient (28:-5) yet updating on PPC principles was thought unhelpful due to the rarity of the event (37:-2). However, training to talk about death and dying was deemed useful (43:5). Unfamiliarity translating adult to paediatric palliative care theory (8:-6), such as doses and medication (2:-6), were addressed in part through advice from specialist nurses (4:4), highlighting welcomed specialist support. “No amount of training would equip a busy GP to deal with this without other experts” (GP 42).

The quarterly meeting was considered important (36:6), as was the GP’s role in updating the out-of-hours service (44:5). However, not all GPs used the out-of-hours service provider, some providing this service. “GPs should always be available to these patients” (GP 54).

**Viewpoint 4: The Pragmatic Practitioner: The rare experience necessitates innovative time management.**

The distinguishing statements for this viewpoint highlighted how pressures on GPs’ time influenced their ability to provide comprehensive palliative care (20:6). GPs were unclear how to initiate contact at the transition to palliation and how often to visit (16:4). Although weekly home visits were perceived difficult (11:6) and limited to a maximum of thirty minutes (22:5), there was evidence of GPs adapting their practice; “Whilst time constraints are a problem it is so rare that rule books are torn up to a certain degree” (GP 49), “Good palliative care just takes time there is no way around it. Sadly routine work time doesn’t allow this it just has to come out of personal time” (GP 12). GPs did not perceive time pressures as barriers to spending time with families, the likelihood of it being a unique experience providing justification.

PPC did not come easily to these GPs (34:-6), the lack of specialist training aligned to their ability to manage the care (41:-5). Learning from specialists was valued (3:5). Translating adult to paediatric palliative care theory was not seen as straightforward (8:-6).



Although the emotional toll associated with working in this field was recognised (47:1, 48:2) GPs did not perceive that they managed their own support needs (10:-5).

## **DISCUSSION**

The four identified viewpoints each provide novel distinct perspectives on factors influencing the role of the GP in PPC that can inform practice. Viewpoints ranged: those who felt their role was important and could be of benefit (Viewpoint 1); those who felt whilst longevity of providing on-going family care was important, they did not need to play a key role (Viewpoint 2); those who welcomed support as they viewed involvement as a challenge (Viewpoint 3); those whose ability to be involved was hindered by time pressures (Viewpoint 4). Although these four viewpoints reveal consensus they are distinct with interesting nuances. Consensus could be attributed to factors such as statement selection and/or wording or limited viewpoints due to the nature of the arena being studied. The concourse (collated interview transcripts) was robustly developed in recognition that the diversity and quality of statements could influence the identified viewpoints. In addition, after completing the Q sort, participants were asked to highlight missing statements or perspectives. When interpreting findings careful consideration was given to the GP level of agreement. Despite clear guidelines for completing the Q sort it is unknown whether their level of agreement was in relation to an 'ideal' world or, as asked for, 'most like practice,' "discrepancy between what a GP would do in an ideal situation and what they actually do in real time" (GP 216). Unknown factors, such as prior personal or professional palliative care experience, may also impact the Q sort. The time taken to complete a Q sort can prove a limitation; however verbal instructions supported by written guidance detailing clear stages facilitated timely completion.

Identified time pressures related to both GP workload and provision of care. Although impact of time pressures on effective practice was one of the highest ranked consensus statements (20:3,3,3,6) GPs still prioritised PPC patients. Time pressures also underpinned the identified challenges faced developing effective relationships with families[3,4,5]. Unlike other disease groups (where a more prolonged period of palliation may provide additional opportunities for GP contact) the recognised often short duration of palliation for children with cancer[4,5] highlights the need for close collaboration with the RCCC. Identified supporting consensus of agreement, such as Statement 15, "Keeping regular contact with the family after diagnosis makes the transition into palliative care easier for the GP" (15:5,1,4,3), although needing to be considered in context as they reflect GPs' anticipated trajectory (those GPs yet to experience PPC), are still valuable in informing practice. Introducing strategies to enhance collaboration between primary and secondary care, such as timely updates and joint (secondary care specialist nurse/consultant: GP) home visits, may facilitate early GP contact, development of a working relationship and aid role clarity.

Viewpoints on GP role ranged from role clarity and ability to identify learning needs (Factor 1) to undefined and challenging (Factor 4). Furthering current knowledge[3] these findings, along with consensus and disagreement between viewpoints, are particularly useful in identifying where strategies can be developed to support and help GPs facing this experience. This study affirms GPs' wishes to play an active role in PPC and their need for specialist education, supporting previous findings[3,10,11]. Moreover findings show that GPs recognise, and strive to address, challenges arising from the rarity of the experience and difficulties developing/maintaining specialist knowledge. In addition to identified specialist education needs such as paediatric symptom management (2:-4,-6,-6, 3), findings support the recognised importance of developing specialist skills (such as communication) in providing exemplary palliative care[6,10]. Findings highlight a range of views on 'straight talking' versus 'skipping around' sensitive issues with families; Factor 1 strongly agreed (46:6) whereas Factors 2 and 3 showed the least agreement (46:-1, 46:-1). Recognition of the benefits of learning how to raise and talk about death and dying with families (45:0 3,3,3) was unanimous. Interestingly despite GPs being generalists and the rarity of the event (37:-2,-3,-2,-3) there was consensus for undertaking specialist PPC training (38:-1,-2,-3,-4) supporting the need for formal PPC training[10,11,27]. The impact of identified time pressures, and ability to attend formal specialist training courses necessitates innovative approaches. Self-directed learning resources covering symptom management and addressing highlighted learning deficits such as discussing sensitive issues with children, are available[28]. However, fostering close collaborative multi-professional working across primary and secondary care settings could facilitate appropriately timed and targeted education, training and support according to individual need. Thought also needs to be given to the emotional toll consensus. Although the importance of having supportive colleagues was recognised (7:4,4,2,2) the potential benefits of support networks developed through enhanced collaborative working with secondary care are unknown. Recognising the importance of multi-professional working in PPC[3], these findings can inform strategies to promote optimal working between primary and secondary care health professionals, directly informing the care provided to the child and family.

The significance of these findings is particularly pertinent given the recognised increasing prevalence of children and young adults with life-limiting conditions[29], the challenges adolescents with complex health needs can face as they transfer to adult services [30,31] and the often long period of palliation associated with non-cancer deaths[4, 5]. Findings highlight the opportunity for a wider pivotal GP role in effectively managing the transition of palliative care from paediatric to adult services.

This study, using QM to examine the PPC views of GPs, provided a unique opportunity for GPs to reflect on statements depicting fellow GP and bereaved parent personal experiences. Through identifying four novel distinct viewpoints, and

exploring consensus and disagreement between them, this study has provided new insights into the differing perspectives on the role of the GP in PPC. The potential benefit of this new knowledge in developing strategies to support GPs providing PPC has been demonstrated, with findings also being applicable to the wider field of PPC.

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