



Heartsink encounters: a qualitative study of end-of-life care in out-of-hours general practice

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DECLARATIONS

Competing interests

MT teaches on the Cardiff University 'Short Course – Essentials in palliative medicine for GPs' based in Wales, which is mentioned and referenced in relation to the research findings; AN has no competing interests to declare

Funding

None

Ethical approval

Ethical approval was obtained from South East Wales Research Ethics Committee

Guarantor

MT

Contributorship

MT and AN designed the study; interviews were conducted by MT; MT and AN carried out the data analysis; MT wrote the initial draft of the

Summary

Objectives We aimed to establish how prepared GPs who work regular out-of-hours shifts feel when dealing with end-of-life issues in palliative care patients, what they thought about seeing such patients and whether they considered themselves emotionally equipped to do so.

Design Semi-structured interviews were conducted with GPs who worked regular out-of-hours shifts. A detailed analysis of transcripts using Interpretative Phenomenological Analysis was undertaken.

Setting South Wales.

Participants GPs employed by the local health board's out-of-hours service were contacted.

Main outcome measures All interview data were analysed systematically and statements that reflected emotional impact and strain were highlighted, coded and interpreted within their context.

Results GPs expressed unease and used terms such as 'heartsink', when having to deal with palliative care issues out-of-hours. Heartsink in this context referred to the subjective experience of the clinician. Emotional 'housekeeping', i.e. looking after oneself after emotionally-charged encounters, was felt to be a very important process and GPs used a range of coping mechanisms, including reflective time, sharing with peers, compartmentalisation and personal empathy to deal with stress.

Conclusion The emotional effects of palliative care encounters on out-of-hours GPs should not be underestimated. Our interpretation distinguished the term 'heartsink' from its usual context, the 'heartsink patient', to a different meaning, that of the imminent palliative care encounter triggering a sensation of heartsink for some out-of-hours doctors. Therefore, the term 'heartsink encounter', rather than heartsink patient, seemed more fitting. Pressed services may encourage a culture where discussion or debrief with a colleague after a palliative care encounter is not perceived as a practical option. This may contribute to

paper and AN made amendments and suggestions; both edited the original manuscript and approved the final version

Acknowledgements

The authors thank Bernadette Coles, librarian at Velindre Hospital NHS Trust for her help with the literature search

Reviewer

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work-related burnout in this group of doctors and out-of-hours collaboratives need to be aware of this issue, when planning their services.

Introduction

Provision of out-of-hours care by primary care physicians is a crucial element of healthcare in many countries, including the UK (Box 1).¹

Studies have shown that general practitioners (GPs) see palliative care as an important part of their work and that they feel they should remain the main providers of this aspect of care.²⁻⁴ However, factors causing a barrier to the provision of effective palliative care have been identified: many GPs no longer having personal patient lists; work-patterns meaning less ownership and continuity of care; and changes in emergency and out-of-hours care provision.⁵ Very little is known about those doctors who take on primary care provision outside normal working hours, when the patient's regular GP is not available to deal with their palliative needs. While a number of studies have looked into different healthcare workers' emotional responses and readiness to see palliative care patients and their carers,^{6,7} there has been less focus on the out-of-hours GP *per se*. Most terminally-ill patients would prefer to die at home.^{8,9} Home deaths are more likely if there are strong care systems in place in the community setting.^{10,11} The out-of-hours setting in general has the potential to be stressful to GPs (not only palliative care encounters) and structural reorganization, fatigue and fear of violence are factors that in themselves have contributed to less GPs providing this service over the last decades.¹²⁻¹⁵

Palliative care encounters have the potential to be challenging and healthcare workers in different settings who are exposed to these sometimes

emotionally charged encounters can perceive them as difficult and a potential contributor to burn-out.^{16,17}

Every primary care organization in the UK has an allocated out-of-hours care provider. At the time the interviews were undertaken for this study, the out-of-hours care provision for the Cardiff health board was organized and delivered by a private multinational called Serco.¹⁸ Wales has an established specialist palliative care service, and generalists including out-of-hours GPs are able to access this service at all times for advice and help.¹⁹

An article previously published from this set of interviews had focused on how out-of-hours GPs felt isolated, how they saw themselves fit into the wider palliative healthcare provider role and dealt with the issue of time-pressure constraints within this pressed, acute service.²⁰ The issue of the emotional effects of these end-of-life encounters and the specific 'heartsink' comments made by GPs were only briefly touched upon in this study, and we therefore felt it deserved a more detailed analysis and discussion, as summarized by this short report.

Methods

Ethics approval was sought from South East Wales Research Ethics Committee and approved.

Doctors employed by Serco out-of-hours service were contacted by sending a letter and participant information sheet. These were devised by the two researchers and were sent out by the out-of-hours service. We chose to include GPs who had worked in the out-of-hours setting for at least one year, in order to ensure they had sufficient experience seeing palliative care patients. Sixty out-of-hours GPs were identified by the out-of-hours service and were contacted by postal mail. Of the 60 contacted, nine GPs came forward and agreed to be interviewed, which was a response rate of 15%. Table 1 gives a brief outline of some of the demographics of these GPs.

Semi-structured interviews were undertaken and audio-taped and field-notes were taken. MT

Box 1

Defining the out-of-hours service

The term 'out-of-hours' in the UK is defined as the period between 18:30 and 08:00 on weekdays, at weekends from Friday evening to Monday morning, and on bank and public holidays.³⁷ GPs work in shifts of usually up to 8 h to look after patients in the community. If a patient needs to be seen, consultations are available at the out-of-hours primary care centre or a home visit is arranged. Doctors work alone and in shift-patterns. Palliative care patients are seen in the community or at the out-of-hours base and many services prioritize them as urgent.

Table 1
Participant information

<i>Interviewee (gender)</i>	<i>Years worked as GP</i>	<i>Palliative care postgraduate training or work experience?</i>	<i>'In-hours' job</i>	<i>Out-of-hours shifts per month</i>
GP1 (female)	6 years	Yes	GP partner	4
GP2 (male)	3 years	No	Locum GP	6
GP3 (female)	24 years	No	GP partner	2
GP4 (male)	2 years	No	Salaried GP	4
GP5 (female)	15 years	No	GP partner	4
GP6 (male)	5 years	No	Locum GP	8
GP7 (male)	18 years	No	Locum GP	8–12
GP8 (female)	3 years	No	Salaried GP	4
GP9 (female)	5 years	No	Salaried GP	2–4

was the sole interviewer for this study and is a specialist palliative care doctor with a background in general practice and also out-of-hours general practice work. A semi-structured interview schedule was used, which explored GPs experience of palliative care encounters in out-of-hours situations and aimed to establish some of the emotional aspects of these encounters. Questions were open-ended and the interviewer (MT) used a non-directive approach, to allow interviewees to develop their own narrative about these experiences. Interviews were subsequently transcribed verbatim by MT. After each interview, MT transcribed data usually within several days to allow both researchers to identify themes that could influence the semi-structured interview schedule prospectively. Thus, the semi-structured interview schedule grew longer as interviews progressed, as is usual for an idiographic qualitative research study looking at newly emerging themes.

The interviews were semi-structured and open questions were asked. The questions 'How does seeing palliative care patients out-of-hours affect you?' and 'How do you cope with difficult situations out-of-hours?' provided a large volume of data on emotional issues GPs were faced with in this setting.

Data analysis

Transcript data were analysed by both MT and AN using Interpretative Phenomenological Analysis (IPA).²¹ This is a research process that looks into making sense of the participant making sense of their own world, while permitting the researcher

to interpret the participant's perspectives.²² IPA is based on an idiographic approach beginning with a single case as a basis to develop more general categories developed in a detailed case-by-case analysis. In other words, topics emerging from the first interview are analysed and create new ideas for more detailed questioning in subsequent interviews. Every interview can create new themes which are analysed in subsequent interviews and researchers can go back to previous interviews to see if newer topics were previously mentioned or touched upon by interview participants.

Each transcript was read several times by both investigators and important reflections and comments were highlighted. Comments were subsequently categorized into themes by the principal investigator (MT) and coded accordingly. AN re-read transcripts and added or grouped topics using the same coding system. AN and MT reviewed emerging findings individually and then agreed the structure of categories.

Results

Two main topics emerged, the first being emotional involvement and 'housekeeping' and the second being heartsink moments.

Emotional involvement and 'housekeeping'

The degree of willingness for emotional involvement varied considerably between GPs interviewed. It was felt that relationships could not be

built, as they could be within in-hours general practice and there was an undertone of the busy service not being compatible with getting overly emotionally invested. However, as interviews progressed it became clear that the emotional ties in palliative care encounters were inevitable, despite these often being one-off meetings.

So lack of continuity I guess, yeah but also lack of emotional involvement, there's not the same relationship you'd have with your regular patients. (GP8)

Most of them you don't know and they don't know you [sighs], it's a different transaction with patients than within the patients you've got to know in-hours. (GP1)

Whether they care [other out-of-hours GPs], I don't mean care, but whether it's just so busy that it's yeah, it's another call, it's a terminally-ill patient. (GP3)

These statements imply that GPs seem to grudgingly accept that the transaction in out-of-hours was not as 'deep' as in day-to-day general practice, due to a lack of an established relationship. All GPs were able to compare directly with in-hours GP services, because they all had jobs in both the out-of-hours and normal working hours setting.

GPs felt that palliative care encounters were more emotionally involving than most 'more typical' out-of-hours consults, due to complex needs of patients and families.

It's more heavy duty than other consults. (GP4)

But yes, looking at it now, I do see it's [palliative care] very complex, it's not straightforward, it's not like the other visits. (GP2)

Also, palliative care encounters stayed with the doctor emotionally well beyond the shift.

I don't think it makes for an easy consultation and I would think about it after, erm. (GP8)

... And you know I go 'Oh god, I've missed some aspect out', but you know that's just me. And palliative care encounters are an area where this is quite more likely to happen, you're certainly more likely

to think about it for than for other consultations. (GP5)

... Only once have I lost sleep... (GP5)

Many out-of-hours doctors used metaphors and figurative language to convey complex emotion. GP7 used a metaphor, that of 'carrying', comparing palliative care to a weight, or perhaps an emotional burden within the out-of-hours context.

... You do carry it home, whether you like it or not, whether you like it or not, we as doctors carry it with us a lot. So, er, you know like everyone else, I do tend to carry. (GP7)

... Likely to stay with you for a long time compared with non-palliation. (GP2)

... You're more likely to remember it for a longer time. (GP2)

GP4 describes his head as 'spinning' after coming home from a particularly palliative care-heavy shift one night, using metaphorical language to describe a state of emotional exhaustion ('drained'). He goes on to say that the emotional involvement is such that some 'house-keeping' becomes necessary:

I've done a shift in the out-of-hours doing lots of palliative care cases. I'd come back, coming back home my head was spinning, I was pretty, pretty emotionally drained. (GP4)

... Coping with the emotional things, I think it's just a bit of 'housekeeping' afterwards, say to the driver let's go and have a cup of tea, don't just go straight to your next call. (GP4)

'Housekeeping' was interpreted as a term sometimes used in general practice education as a metaphor for doctors needing to look after themselves especially after difficult consultations.²³ Several GPs also pointed out that emotional debriefing was a necessity after out-of-hours palliative care encounters, feeling, in some cases, the need to give themselves permission to be sad and to feel their humanity, as though this was a negative or unwanted feeling or attribute as a doctor.

...but I do allow myself to be sad, because, erm [silence for 3 seconds] because I'm [silence for 2 seconds] because I'm human and I can't not be sad, and I think if I would try not to be then I'd find that would make me very hard. (GP5)

... So I do allow myself to be sad... (GP5)

GP5 appears to also want to deal with this emotionality, like an actual entity, a process that has a start point and a finish point ('finished that') and can then be ticked off (I've completed that') and moved away from ('I don't say I'll deal with that emotionally later'). Her coping mechanism appears to be compartmentalisation of the negative emotions associated with the stress and burden of responsibility:

... Once I've finished that, I feel quite able I've completed that, I don't say 'I'll deal with that emotionally later'. I kind of try and do it at the same time, so that I don't have to take it away and mull over it. I mull over things and I get paranoid, where I think I've missed something, you know, I get really stressed... (GP5)

Even a two-minute pause is appreciated after such encounters, emphasizing the importance of the reflective process, or, as this GP put it earlier, the housekeeping process:

Can't necessarily do that when it's really busy, but sometimes even just a two-minute pause, erm, I find quite helpful. (GP4)

While GP2 sees the need to discuss these matters with friends or colleagues, more so than other types of out-of-hours encounter, as does GP1:

... You're more likely to discuss it with other, friends or colleagues. (GP2)

I would just maybe think about that myself really or speak to my husband about it, or maybe colleagues. (GP1)

Some doctors, apart from fear and sadness, mentioned the emotion of anger and frustration in the context of out-of-hours palliative care encounters, which they perceived as an immediate stress response.

Erm [loudly]. It [palliative care encounter] affects in a way, straight away feelings of fear, frustration, sense of, erm, lack of co-operation, lack of guidance... (GP7)

And then you more or less get pissed off with the relatives and you get pissed off with the patient, and that's, that's absolutely unprofessional, but that's a human thing, that's... you're frustrated... (GP6)

... It's not the patient's fault, it's not the relatives' fault, it's not a rational response, erm, and obviously, you know. But you, initially the knee-jerk, you see something like this and you say 'Oh! God!' (GP6)

GP6 rationalizes his thoughts by stating that it is no one else's fault, but describes it as a 'knee-jerk' emotional response.

One GP felt that personal experience had shaped his emotional response and handling of palliative care problems:

I don't feel upset by it, I do feel that sometimes when I see palliative care patients, it's more heavy duty than other consults in that I remember a couple of occasions where I've become quite emotionally involved, and erm... So that comes into your mind before you see or speak to them on the phone I guess, it's going to be that bit harder, on different levels. I think, I mean, my mother's been ill lately, and that's changed my, erm, emotional response to palliative care problems, I feel much more, well, more empathy perhaps than I used to. I don't think I was unsympathetic before but, erm, I didn't take it too personally, and I think I perhaps do now, so, erm. To me I see them as important cases, 'cos I've realized how important it is, when, in this setting, when things are teetering on the brink for a whole family all the time, 24 hours a day, that you don't leave the acute crises to brew... And I think it made me appreciate, I think how much, less able families are in that circumstance to cope with the crisis, they've already used up most of their coping reserves, and you have to be very aware of that when speaking to them and so, when, [silence for 2 seconds] previously well-controlled symptoms aren't being controlled any more, erm, people are really struggling and families are put under enormous pressure, the patients are under pressure, their carers are under

pressure and I, it is right that you do the best that you can with those patients. So yeah ... I find it more emotionally involving now. (GP4)

In fact, three weeks later GP4 contacted the researcher to explain that his mother had passed away, having suffered from metastatic cancer, which puts the above statement into a deeper emotional context and clearly reveals how his attitude to patients has changed due to personal life experience.

'Heartsink' moments

Doctors' initial response to palliative encounters out-of-hours was often worry and what some described as an emotion of 'heartsink', as exemplified by the following statements. Three GPs of the nine interviewed brought up this terminology independently without prompting and we have provided some examples below. GP1 for instance feels mainly overwhelmed, indicating a perceived lack of control or confidence, but one gets the impression that GPs interviewed have a number of anxieties when it came to out-of-hours palliative care issues:

Erm, so how does it affect me, to get back to what you're asking, erm, so... More of a challenge, I would take my time, I would maybe, feel, mainly a bit more overwhelmed... (GP1)

Ok, it's, I don't take it for granted that it's easy [silence for 2 seconds], you do sort of, look at it and think it's a bit of a heartsink moment. (GP2)

I do find it, erm, a bit more difficult issue to kind of deal with initially, I get more nervous maybe when I'm seeing, about to see a palliative issue... (GP2)

I do sort of see these as heartsink patients... (GP2)

GP2 tries to mitigate the blow of his high impact statement by using the qualifying phrase 'sort of' when he says 'I do sort of see these as heartsink patients'. Perhaps saying 'These are heartsink patients' or 'I see these as heartsink patients' is too direct, too honest, even too much of an admission, that could, in his view, expose him as less compassionate towards these very unfortunate patients, than he would like.

GP6 in particular, uses the word 'heartsink' frequently. He has many negative thoughts before seeing palliative care patients out-of-hours and actually relieves this fear in the interview by using the shock exclamation 'oh gosh'. He also equates his fear of out-of-hours palliative care with the fact that such cases are in 'complete chaos', and that the out-of-hours doctor is 'dumped with that':

... You already know it's palliative care and you usually get a heartsink feeling because you know this is going to be difficult. (GP6)

Oh gosh and literally, it's a heartsink patient. (GP6)

... This is going to take a long time to sort out... (GP6)

... And obviously you will know those cases best, which are heartsink, frustrating, complete chaos and you've been dumped with that, but often it's just the processes involved, which is frustrating. (GP6)

Discussion

There appeared to be for GPs a juxtaposition of conflicting feelings when faced with a new palliative care encounter out-of-hours, one of worry that too much emotional involvement could negatively impact with service provision in an acute community setting and the other of a sense of inevitability of being emotionally drawn into these encounters. The reason for this may be that despite a wish for emotionally 'steering clear', they could not avoid being drawn in, and often took the sadness or worry about the patient home with them. This 'inevitable' emotional involvement made it necessary for them to have some kind of debriefing, be it with a fellow colleague or a relative. Emotional 'housekeeping',²⁴ looking after oneself following emotionally charged encounters, was felt to be a very important process and GPs used a range of coping mechanisms, including reflective time, sharing with peers, compartmentalisation and personal empathy to deal with stress. Lack of teamwork in the isolated out-of-hours setting appears to be a risk factor for stress and emotional burden. Well-performing teams do so because they are able to support each other, can

notice when one person is underperforming or appears stressed, and can step in to help.²³ These support structures do not seem to exist within out-of-hours care and doctors we interviewed described having to debrief with external agencies, such as family members to lessen the impact that some of the palliative care encounters had on them. Furthermore, none of the GPs in our study commented in particular about the stress of holding two or more jobs (in-hours and out-of-hours), but this may have added further to perceived levels of stress and lack of support structures.

In a survey of British GPs, out-of-hours on-call shift work was associated with higher levels of anxiety and depression among this group of doctors. Also, single-handed GPs experienced higher levels of depression.²⁵ This could, in theory, raise concerns about the work pattern within the out-of-hours GP setting, but little research exists on this topic. Moreover, defining out-of-hours GPs is difficult, as the present arrangements in the UK mean that out-of-hours work is a salaried shift job, and as this study shows GPs usually have another 'in-hours' GP job.

GPs felt that there was less scope in the out-of-hours setting for getting emotionally involved with patients, in contrast to the in-hours setting. Perhaps this is mainly due to time constraints in the busy out-of-hours setting; but it may also be a protective mechanism, as GPs looking after distressed people have to become more effective at 'rationing their compassion and to become more emotionally detached for their own sakes' as argued by O'Dowd.²⁶

The 'demand-control imbalance' model by Karasek²⁷ postulates that jobs are stressful if they have both high demands with little or no power to alter the situation. Perceived low control is considered a major source of work-related stress.²⁸ Out-of-hours GPs felt that their interventions in the setting were limited by the fact they could only see palliative care patients once, had little to offer and expressed clearly their feeling of powerlessness and frustration in this setting.

'Heartsink' in the context of the interviews, referred to the subjective experience of the clinician. This stands in contrast to the more usual definition of the 'heartsink patient' in the medical literature,^{29,30} which describes frequently

attending patients in general practice or specialist settings. Groves, a psychiatrist, defined them as four stereotypes: dependent clingers, entitled demanders, manipulative help rejecters, and self-destructive deniers.³¹ This definition does not fit with the palliative care patients seen by the GPs interviewed in this project. Both researchers interpreting these interview extracts agreed that therefore the 'heartsink moment' for GPs is the actual realization of an upcoming difficult encounter or a particularly stressful or emotional palliative consultation, rather than a label for the palliative care patient *per se*. An essay in the *British Journal of General Practice*³² comes to a similar conclusion, after reviewing the use of the term 'heartsink' in the medical literature for the year 2010; the term itself appears to have shifted far from the original meaning, contextually and semantically. The author suggests we shift away from the more traditional patient-labelling approach and instead think more in terms of 'heartsink relationships'.

With regard to the sample size of this study (nine participants), it is important to note that IPA studies focus on smaller numbers but larger volume of data from individual participants. Therefore, compared to quantitative research that focuses on larger numbers and reproducibility, IPA studies frequently focus on a small number of very specific people and unusual, outlying statements become the focus of attention. Smith has suggested three to six participants as a reasonable size for an IPA study.³³

One of the limitations of this study was the fact that the nine GPs who came forward were likely to have been a more motivated sample of out-of-hours GPs. Also, six out of the nine GPs interviewed had worked as GPs for less than six years, and this may have been one of the reasons that terms such as 'heartsink' and 'housekeeping' came up, as they may well have been covered in recent vocational training schemes.

Conclusion

Out-of-hours GPs found palliative care encounters highly emotionally charged and saw them as heartsink encounters. GPs took 'emotional baggage' with them and felt the need to debrief or 'housekeep' after consults. Pressed services may encourage a culture where discussion or

debrief with a colleague (other GP or on-call specialist palliative care service) after a palliative care encounter is not perceived as a practical option. This may contribute to stress in this group of doctors doing isolated shift-work patterns and out-of-hours services need to be wary of this issue. GPs' own personal experiences with family members having palliative care had a potential to shape consultations and create an emotional resonance.

The Welsh 'Implementation of Palliative Care Report Palliative Care Services funding 2008 to 2009' has stated that 'The education and training of the NHS Wales' workforce is a core duty of specialist palliative care services.³⁴ A number of trusts and health boards across the UK now offer palliative care courses for generalists. One such example in Wales is a GP-focused end-of-life care program called the 'GP short course on palliative care'. It was successfully piloted in Pembrokeshire and is now run regularly across Wales, with good uptake from GPs working in the out-of-hours setting.^{35,36} There is a need to continue strengthening these efforts, and to find strategies for how GPs working isolated out-of-hours shifts are able to improve their end-of-life care resources and knowledge, develop strategies to prevent burning out emotionally and get hold of specialist backup easily when crisis situations occur.

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