Title: Opinions of Acute Clinicians to Patient Held Records for Palliative Patients: An exploratory pilot study

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Introduction and background

Health care professionals often find bringing up the subject of dying uncomfortable; this is particularly difficult for clinicians in the acute sector where a biomedical model of 'cure' prevails [1]. Clinicians also feel guilt that if end of life issues are discussed, patient's hope and morale will be diminished [2]. However, advanced care planning and increased information about end of life has been found to positively enhance hope in palliative patients rather than diminish it [3]. In a study of the prominent psychological factors that influenced clinicians when caring for palliative patients, findings show clinicians try to do the right thing at the right time, but are hindered by not understanding the journey or trajectory of terminal illness [3]. Concerns identified include: a lack of knowledge as a result of not knowing the patient; not understanding the rate of patient disease deterioration; not having access to patient investigations, and; not having patient wishes documented [4,5].

In the United Kingdom (UK) individualised care planning is an ideological concept in palliative care, rather than a common place practice [5].

Literature review

Patient Held Records (PHRs) have been used in other areas of health care for many years and their use has resulted in greater communication and improved control for patients [6,7]. One study undertaken found that there was no strong evidence as a basis for promoting the use of PHRs in palliative care, but this may have been due to the lack of compliance by acute clinicians to the use of PHRs [8]. In the study, clinicians in the community sector were consulted on PHRs before their implementation, while clinicians in the acute hospital were not. The community clinicians were twice as likely to report positive feedback on the use of PHRs in palliative care as the acute clinicians [9].

Following a recent three-month Japanese trial of PHRs in cancer/palliative care, patients findings showed that the PHRs were useful in facilitating communication, increasing patient understanding of their medical treatments and disease, and facilitating end of life discussions between patients and clinicians [10]. However, one of the main obstacles to the widespread implementation of PHRs is the undervaluing of PHRs by the medical professionals [10]. There has been no research into the views of acute sector clinicians to the implementation of PHRs in palliative care.

Poor communication between the acute and community sectors leads to avoidable admissions of palliative patients into hospital [11] . Inadequate information given by acute clinicians to palliative patients and their carers about their discharge and care needs, leads to palliative patients feeling dis-empowered and not in control [11]. Nurses caring for palliative care patients in the acute sector identified that a lack of information about their palliative patients hindered care [12]. Furthermore, when palliative patients are admitted to the emergency department, the emergency clinicians have little information about them, which leads to a defensive and bio-medical approach to their care, which in turn generates multiple inappropriate investigations and tests [13].

A UK study of 183 palliative patients admitted to hospital showed that there was no evidence of individualised advance care planning [14], despite the fact that the UK End of Life Strategy [15] highlights the need for advanced care planning for palliative patients. Palliative patients who have an individual plan or pathway are less likely to be admitted to hospital than those that do not [16], had better physical health and received better holistic care [17]. Findings showed that if sharing of information between on-call doctors and the acute sector had occurred, then admission of some palliative care patients could have been avoided [18].

Patient Held Records

Research of PHRs for palliative patients has shown that they increase communication between patients and staff, and between staff and the patients' families. Patients reported an increased understanding of medical conditions and treatments and indicated that they had a better understanding of the current state of their disease. PHRs facilitated end of life discussions and patients were able to declare their preferences for preferred place of death and treatment choices [10]. However, the main obstacle to the implementation of PHRs was the undervaluing of the role of PHRs by medical professionals [10].

In an Australian study a combination of 5 tools were used to improve palliative care, one of which was PHRs [19]. Findings showed that when PHRs were used for palliative patients, visits to emergency departments were less stressful for them because all the information was there [19]. Using PHRs generated discussions about symptoms, thus allowing symptoms to be better addressed by clinicians. [19]

The Current Study

Research question:

This pilot study set out to explore the question: What are the views, themes and opinions of senior clinicians in the acute sector to PHRs in palliative care?

Research Approach and data collection

A descriptive phenomenological approach was selected for this research study [20]. This was a pilot study on a purposive sample of nursing and medical clinicians working in acute hospital care (n=8). Participants were doctors at consultant level and nurses at Band 7 or above, all of whom worked in an acute hospital and all of whom cared for palliative patients as part of their everyday workload. Data was collected using semi-structured interviews. Each participant was asked 12 pre-set, open-ended questions and each interview took between 25 and 40 minutes to complete. All interviews were digitally recorded and transcribed.

Ethical approval

Prior to the commencement of the study ethical approval was obtained from the researcher's university and from the acute health trust where the participants worked. Confidentiality and anonymity were assured and all data was stored on a password-protected computer to which only the researcher had access.

Findings

Five clusters of findings were identified from the data, 3 positive and 2 negative.

Insert Figures 1 & 2 here

Positive theme cluster 1: PHRS will empower palliative patients

Empowerment and control for palliative patients was a recurring theme expressed by the acute clinicians, who saw PHRs as a tool to achieve it.

> *"I think it's empowering for patients."* (Clinician 2)

> "*I think it would give patient's ownership of their notes. They would feel things were not being held back from them."* (Clinician 5)

When the acute clinicians were asked what information should be included in the PHRs, they predominantly wanted patient preferences documented.

> *"I guess its [PHR's] key priority is when you can't communicate with that person because they are too unwell to vocalize things, where are their priorities in terms of where they want to be looked after and the level of intervention that they are looking for? So [PHR's would be] a guide to what is their fundamental wishes."* (Clinician 1)

> *"Information should be patient led…... you have to make it right for them."* (Clinician 3)

Positive Theme Cluster 2: PHRs allow the acute clinician to facilitate a holistic and individualized patient plan

Acute clinicians empathise the need for holistic assessments of palliative care patients to be documented in the PHRs.

> *"I wonder if there is an area in there [PHRs] for more of the social side, what kind of support is there at home. If there is a carer going in there, [patient's home] there may be a separate folder for that. It's important in palliative care that we know how they are supported, psychologically and socially as well."* (Clinician 8)

Acute clinicians indicated that if they were palliative care patients they would want to have their own PHRs.

> *Yes, I absolutely would [want a PHR for myself], I think it is a very empowering experience to be used as a tool to negotiate your care."* (Clinician 2)
>
> *"I would like to keep in control of things and write things down. I would like to be in control of my disease and my own treatment and I feel that PHRs might help that."* (Clinician 3)

Acute clinicians expressed anxiety about not "getting it right" which reduced their own sense of professional achievement.

> "*…So I think there is a concern for the patient [by the clinician] about 'doing it properly' and `well'. You want to be kind and helpful and not cause distress."* (Clinician 1)
>
> *"I want them to fully understand what is happening……..but still have hope that their treatment is right and they will be cared for properly. It's a difficult situation."* (Clinician 5)

Positive Theme Cluster 3: PHRS facilitate interprofessional working

Access to different computer systems is often a barrier to sharing information between clinicians in different health sectors.

> *"We have ….. electronic records, but we are not always able to access [them] …….. a lot …. is done outside the hospital …… so communication between District Nurses, General*

> *Practitioners or palliative care teams, community nurses - we don't see that. We don't know what has been discussed or agreed in other areas."* (Clinician 1)
>
> *"In palliative care people are under a lot of different teams and accessing information from teams can be quite complicated with computer records. It would be useful to have the information at our finger tips."* (Clinician 8)

The clinicians highlighted that PHRs would enhance communication across health sectors.

> "S*ometimes we don't know a lot about histories and I think this is a challenge. Often patients have a complicated history and they come in from localities. The benefit I would see is they [PHRs] work across different sectors, so if someone has a diagnosis of prostate cancer, they would be involved with the urologists, the community nurses or perhaps the community palliative care team, and an oncologists and the correspondence between all of those may not be clear when they come into the acute sector."* (Clinician 1)
>
> *"You are giving the information to pass from primary care to secondary care; it's not just for the patient, but for the clinicians as well" (*Clinician 7)

The acute clinicians highlighted the need for the preferred place of care of the patient (PPC) to be seen across health sectors, which would lead to transparency of care. The lack of a detailed plan for palliative patients, according to the acute clinicians in this study, leads to palliative patients PPC not being achieved.

> ”*When I was a patient, I was fortunate enough to see what people had written down about me ... a tool to negotiate your care"* (Clinician 2)
>
> *"They [palliative patients] wouldn't have to keep repeating themselves about their wishes, which in itself can be exhausting. The same old issues when in fact they have dealt with them and they need to carry on with living."* (Clinician 6)

Negative Theme Cluster 1: PHRS will not be used by all health sectors

Acute clinicians expressed concern in terms of having to comment on the opinions of other clinicians. Other concerns included lack of compliance by clinicians to filling in the PHRs in a timely fashion and how to fill in PHRs accurately if palliative patients deteriorate rapidly.

> "*A clinician might feel put on the spot about another clinician's practice. I can imagine that somebody might say "so why did Dr X do Y?" and if it's written down, I may be put into a position on wanting to comment on that."* (Clinician 2)

> *"Well any record is only as good as the person filling them in, so it's likely any documentation, if it's not kept up to date by people …….. will miss things."* (Clinician 3)
>
> *"They do need to be regularly updated so the most can be got out of them; I think there will be a point as the patient begins to deteriorate it might not be important for them [the palliative patient.]"* (Clinician 5)

Negative Theme Cluster 2: PHRS will increase the palliative patient's burden

Acute clinicians perceived that for some patients having the information written down about their disease and prognosis may increase anxiety and confusion, rather than alleviate it.

> *"The difficulty would be the element of compromise; you would put things in there that were pertinent and already discussed with the patient. You would err away from anything I suppose, theorizing, supposing differentials that would be frightening for the patients."* (Clinician 1)
>
> *"Patients of a certain generation may think they don't want that responsibility; it's the professional's responsibility to take notes. Some patients do not want to read and know about their care."* (Clinician 4)

Some acute clinicians expressed the opinion that in certain circumstances PHRs may lead to patient confidentiality being compromised.

> *"Relatives may pick up the paperwork without the patient's consent, when the patient is too poorly to give consent."* (Clinician 6)
>
> *"Something in their possession might be read by others who might have a sneaky look at it!"* (Clinician 8)

Discussion

Positive cluster 1: Empowerment and control for palliative patients

When palliative patients are more involved in decision-making, they have a better quality of life, fewer hospital admissions and longer survival rates, concluding that there is a need for advance shared decision-making in palliative care [, 21]. The acute clinicians in this pilot study see PHRs as a way of achieving shared decision-making between the patient and the clinician, supporting previous studies [22.]

In a seminal British research study into the use of PHRs in cancer palliative care, it was found that 14% of the 80 patients in that study did not use their PHRs [8]. The reason cited for this was that the PHR had been introduced too late in their disease trajectory and they felt too ill to participate. In a Japanese study of PHRs for palliative cancer patient, patients wanted to leave messages to their family and clinical staff in case they deteriorated [10]. A separate study of palliative patients in the acute sector found that although Advance Care Plans (ACP) are advocated by all UK national polices for end of life care, none of the participants in their study had a care plan when admitted to the acute sector [14]. This would seem to suggest that although ACPs are seen as the gold standard for palliative care in the UK, they are not being implemented. It may be that PHRs for palliative patients could address this issue.

The acute care clinicians in this pilot study identified the importance of patients and their families being involved in decision-making in end of life care (EOLC). Previous studies have shown that where families and patients could not be involved in decision-making, it led to them feeling they were rushed into decisions about EOLC [23]. These families were also far less likely to describe the death of their loved one as a "good death" as opposed to families that perceived they had enough information [23].

Positive cluster 2: Patient held records for palliative patients allow the acute clinician to facilitate holistic and individualised care

The clinicians in the current study felt PHRs would facilitate holistic care, supporting previous findings that palliative patients and carer perception of good care was three fold – good physical symptom control, good psychological support and a reliable liaison with other agencies or health teams [24]. Clinicians who support patients at the end of life, and who encompass both biomedical and psychosocial aspects of palliative patients care in their practice, viewed their clinical practice as very satisfying [25]. This may suggest that the documentation of both biomedical and psychosocial assessments in PHRs for palliative patients would not only benefit the care of the palliative patient, but help with the emotional wellbeing of clinicians in palliative care.

Positive cluster 3: Patient held records for palliative patients would facilitate interprofessional working

A well-defined and written care plan, viewable by all health agencies, would enhance interprofessional working in palliative care [26]. The recent Japanese study of PHRs for palliative care patients showed that as hospitals become more specialised, this can result in fragmented care for palliative patients and unorganised treatment [10]. PHRs can address this problem by the sharing of information across different health agencies [27]. The acute clinicians in the current study support this and express their need to know about the patient's previous clinical investigations by other health agencies. They also wanted to know more about the social and home environment of their patients, to enable them to plan an appropriate discharge. They felt that PHRs could provide this information.

Negative cluster 1: Patient Held Records for palliative patients will not be used by all health sectors.

A previous UK study found that poor communication and information-sharing between health agencies was a reason for early re-presentation to the acute sector after the discharge of older and palliative patients [14].

Two previous trials of PHRs for palliative patients found discrepancies between community and acute clinician's opinions of PHRs, with community clinicians being more positive and seeing a greater value in their use [8, 9]. This may be partly explained in the first study by the fact that PHRs were used by the community clinicians as the sole record for their patients, while the acute sector clinicians had to fill in the PHRs in addition to existing medical records [9]. Also in the second study community clinicians were consulted before the implementation of the PHRs, while the acute clinicians were not [8]. There was therefore an uneven playing field in their introduction across the acute and community sectors.

5. Patient Held Records for palliative patients will increase the palliative patient's burden

Acute clinicians expressed the opinion that for some palliative patients, PHRs may increase anxiety and confusion rather than alleviate it. A previous study into the provision of written information in palliative care found that information - such as letters between health professionals - seen by the palliative care patients could cause confusion, difficulties of comprehension and interpretation for some patients [28]. However, for the majority of palliative patients in that study the patients gave this information a high value as a source of personal information [28].

The acute clinicians in the current study also expressed their concern that for some patients the responsibility of PHRs would be too much. The Japanese study into PHRs for palliative care reported that some patients did not want the responsibility of the PHRs and did not want to participate in the decision-making process [10], with 15 out of the 50 patients expressing the view that taking notes with them was a burden. They said that they had no energy left to write their own notes and sometimes stopped using them [10].

For some patients written information about the likely trajectory of their illness was best given verbally, but an equal number expressed that written information was vital [28]. Having a rigid format for PHRs for palliative patients is not recommended and the information has to be guided by what is right for the individual.

A concern of the acute clinicians in the current study was the potential breaking of patient confidentiality if PHRs were introduced. This too was found to be a concern expressed by the Japanese study [10], where some patients were reluctant to participate in PHRs as they feared others knowing their true feelings about their illness.

Although the acute clinicians in the current research had some negatives opinions of PHRs, when asked if they would want their own PHRs if they became a palliative patient, all replied positively, citing a need to want to be in control, know all the information available and plan their own care with the clinician looking after them. Although the current study did not explore this in great detail, a previous study of physicians looking after doctors with advanced cancer, found that the major theme for the doctor-patient was the need to be in control, to have self-management and to direct their own care [29]. This appears to demonstrate that there is lack of congruence between what acute clinicians think is right for the patient and what is right for them.

Limitations of the Current Study

Further research would need to ensure the transferability of these findings by using a larger sample size, more than one clinical setting and by extending the participants to other clinical groups. In addition, opinions around sensitive issues such an End of Life Care may vary due to the culture, age and experience of participants. A larger study would be able to document these variables and assess their significance.

Conclusion

PHRs for palliative patients is a simple and practical way of putting the patient back into the centre of their own care, by promoting transparency in the management of their treatment in the acute sector. Most importantly, the implementation of Patient Held Records in palliative care would result in more palliative patients achieving their preferred place of care at End of Life.

However, to date there has been no single study that has sought the opinions of all service users and providers into the implementation of PHRs in palliative care and this is needed to form a consensus on their future implementation.

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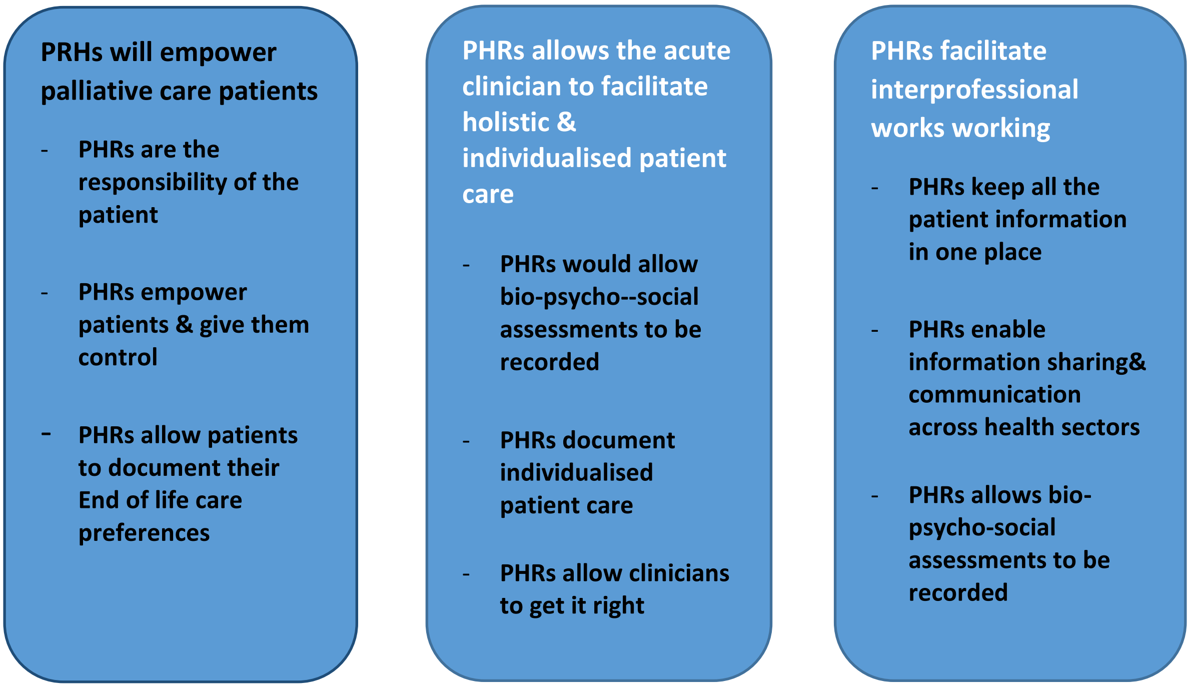
Figure 1: Positive revelatory themes into 3 main clusters



PRHs will empower palliative care patients

- PHRs are the responsibility of the patient
- PHRs empower patients & give them control
- PHRs allow patients to document their End of life care preferences

PHRs allows the acute clinician to facilitate holistic & individualised patient care

- PHRs would allow bio-psycho--social assessments to be recorded
- PHRs document individualised patient care
- PHRs allow clinicians to get it right

PHRs facilitate interprofessional works working

- PHRs keep all the patient information in one place
- PHRs enable information sharing& communication across health sectors
- PHRs allows bio-psycho-social assessments to be recorded

Figure 2: Negative Revelatory Themes into 2 main clusters

PHRs will not be used by all health sectors

- PHRs information needs to be correct & up to date to be effective
- PHRs will be seen by acute clinicians as adding to their workload

PHRs will increase the palliative patient's burden

- PHRs will cause patient anxiety & confusion
- PHRs are a responsibility that patients do not want
- PHRs are too accessible so will break confidentiality