How can patient and carers' experiences shape services?

The importance of palliative care is something that should not be underestimated. The ethos behind palliative care is to improve the quality of life, first and foremost for the patient facing a life limiting condition but also for their family who are supporting their loved one whilst also contemplating their loss. Palliative care has been designed to alleviate suffering by identifying and assessing the needs associated with many problems a patient may encounter, including physical, spiritual and psychological issues (The National Council for Palliative Care, 2018). It is therefore incredibly important that we are able to assess how well we can achieve these outcomes for the patient and their families and also that we are able to improve the services we deliver to some of the most unwell patients across the UK at an extremely difficult and vulnerable time of their lives.

Quality Improvement projects are always ongoing in almost every aspect of medicine. In palliative care, it is really difficult to assess for improvement due to the nature of the speciality (Chen *et al*., 2014). Measuring outcomes in palliative care can be quite subjective and so a more holistic approach must be used for this. We need healthcare improvement projects to run to allow us to shape our services and improve the standard of care we deliver (Batalden and Davidoff, 2007). Through this essay I hope to portray some ways in which I feel our service could be improved through patients' experiences.

It has been illustrated that patient outcomes are a vital measure in palliative care (Bausewin *et al*., no date). Prior to this, aspects of palliative care that were prioritised included process and resource factors such as patient: staff ratios, sum of admissions and the duration of stay. (Witt *et al*., no date) It is increasingly recognised that it is also important to evaluate outcomes for individual patients and their family. A palliative care outcome measure (PCOM) is much more patient centred, taking into consideration their psychological well-being as well as their physical health and understanding what is important to them (Tavares *et al*., 2016). These outcome measures are analysed and evaluated to determine how we as healthcare professionals can assist to change these over time – whether we can make an improvement or whether we can prevent a further decline by intervening. PCOMs are at the heart of patient centred care and have played a part in improving the quality of palliative care already being delivered (Etkind *et al*., 2015).

One commonly used PCOM is the Palliative Care Outcome Scale (POS). It was developed in 1999 as a brief questionnaire which enabled patients to rank the issues that affected them the most (Schildmann *et al*., 2015). POS takes approximately 10 minutes to complete (Witt *et al*., no date) and the scores can be used by the multidisciplinary team to prioritise problems and focus on the areas which matter most to the patient. Unfortunately, due to the nature of the population, some patients are simply too unwell or fatigued to be able to concentrate for the 10 minutes required. Feedback from both staff and families has informed refinement of the tool and led to development of a condensed, modified version - the Integrated Palliative Care Outcome Scale (IPOS) (Witt *et al*., no date). This shorter questionnaire which is available in multiple languages, was developed by combining the most relevant components of POS with some additional holistic domains. It is ideally completed by the patient but can also be completed by a proxy – either staff or the family – based on their judgement of the patient. It is recommended that IPOS is repeated (every three days for inpatients and weekly for outpatients) as a means of measuring changes in a patient's problems (Witt *et al*., no date).

I am currently involved in a service evaluation at Roxburghe House, Dundee (a palliative inpatient unit with twenty four beds). Our aim is to identify the most severe problems and symptoms encountered by patients using IPOS and assess how they change over the course of admission. All patients admitted to Roxburghe House are asked to complete an IPOS questionnaire on admission as part of routine care. Problems identified as being either severe or overwhelming (scored '3' or '4') on baseline IPOS, are repeated weekly thereafter, along with other measures which capture the patient's overall condition. These additional measures include the Patient Performance Scale (PPS) and, for cancer patients, the Palliative Prognostic Index Score (PPI). For this evaluation, the decision was made that only the patients who were deemed well enough to complete the IPOS independently would be included in order to avoid any discrepancies which had previously been highlighted by the staff version of IPOS (Tavares *et al*., 2016). As yet, not all of the data has been collected and analysed. Preliminary results show that of the 49 patients studied so far, 30 (61%) were unable to complete an IPOS questionnaire independently. This compares well to a study (Etkind *et al*., 2015) which revealed that 57% of their patients needed assistance in completion of their PCOM. The most severe problems reported by patients in the ongoing study are pain (74%), poor mobility (63%), family anxiety (63%), weakness (58%) and poor appetite (53%). So far, there has been a limited amount of data recorded to adequately illustrate the changes in severity of symptoms for patients over time. This is because the condition of patients deteriorates over the course of their admission and they become too unwell to repeat the IPOS; over half of the patients studied so far have died during their admission. This factor alone, illustrates just how difficult it is to evaluate outcomes and measure the quality of care being delivered to palliative patients.

So, do PCOMS like IPOS have a role and how can they be used to improve patient care and develop services?

In my opinion, it is vital that we use a PCOM to evaluate the needs of our patients, although this should be on a larger scale to have the maximum effect on improving our service and caring for our patients. An inpatient setting is caring for the frailest of our palliative patients and so it is not surprising that more than half of them are too unwell to complete IPOS. However, as some are still able, I feel it is important to continue using this in an inpatient setting, albeit that the sample population is a small percentage of the total number of patients on the ward. Furthermore, it has become evident that the use of PCOMs may have greater potential in palliative care patients in other settings e.g. outpatient clinics or hospital wards (Etkind *et al*., 2015).

Even if a patient becomes too unwell to repeat the IPOS, there is still a clinical value in using it as a screening tool to support a comprehensive holistic assessment and to prioritise needs. This can help patients to feel empowered and involved in decision making and the planning of their care (NICE, 2012). I feel that although this may only benefit some of our patients in an inpatient setting, it is still important to involve them in their care as much as possible.

One suggestion that could potentially be implemented would be that each patient with a life limiting condition is provided with an ongoing IPOS questionnaire. Ideally this could be created in the form of a logbook or potentially through the use of SMART technology in the form of an 'app' for mobile phones or tablets - especially for younger patients. Patients could fill in information, as often as they feel inclined and keep it with them to show anybody involved in their care such as their GP, Macmillan Nurse or District Nurse. This continuous questionnaire could be taken to any hospital appointment or admission to show the staff looking after the patient which problems each individual patient is encountering and how these have changed over a longer period of time, rather than just the snapshot that we can obtain during one admission to an inpatient palliative care setting. Ideally staff would be able to intervene earlier to try and control the most troublesome symptoms and ultimately avoid an admission to hospital wherever possible.

In addition, the aging population, coupled with an increased demand on the NHS, has led to an increasing number of palliative patients dying in general wards. Unfortunately, due to NHS pressures, many healthcare professionals looking after these patients may not have the expertise required to deliver optimal palliative care (Levack, 2014). In just under 63% (approximately) of all deaths, patients have had a palliative care requirement (Murtagh *et al*., 2013) as they approach the end of their lives. After all, it would be impossible to deliver end of life care to every patient either in a hospice or at home. If a patient was able to continue completing a PCOM in their logbook or 'app' during their admission and all staff had a better understanding of the importance of this, our service could easily be improved. This might enable staff on any ward to feel more confident in delivering palliative care and would allow them to establish a better rapport with the patient.

Many hospitals have palliative care wards but in our modern day NHS, bed shortages are commonplace in most hospitals, regardless of what speciality, and therefore, there will always be patients nearing the end of their lives in general wards. We often hear of patients not wanting to 'bother' staff, as they can see how busy they are especially if it is obvious that a ward is short staffed. If they are not asked specifically about certain symptoms included in PCOMs, they may not feel able to voice how they are feeling on a general ward as they may not feel the nursing or medical staff have time for them. In the majority of general wards, the aim of the treatment is to improve the patient's condition and ultimately discharge them back to the community. Again, due to increasing NHS pressures, this is often too early and may result in a failed discharge (*A report of investigations into unsafe discharge from hospital*, 2016). Many palliative patients are admitted to hospital for a specific, acute problem from which they are expected to recover, just like any other patient e.g. for an infection that requires IV antibiotics. These patients may well recover and be discharged appropriately. However, it is important to remember that in the case of palliative patients, a time will inevitably come when they unfortunately, will not recover due to the progression of their life limiting condition and ultimately, they will die. The quality of life for palliative patients is often more important than the quantity (Etkind *et al*., 2015). If they are unlikely to recover from an infection, and their stay in hospital is detrimental to their quality of life, this needs to be addressed. This could be conveyed to staff earlier through the aid of an ongoing PCOM, thereby improving the overall care of the palliative patient.

To conclude, we are able to improve our services in palliative care through the use of a Palliative Care Outcome Measure such as IPOS. Palliative care is an aspect of medicine which all of us will encounter at various stages of our professional careers. If a PCOM could be used throughout the patient’s entire journey regardless of the setting they find themselves in, we should be able to deliver a higher standard of care and improve the patient’s overall experience. It is vital that we encourage various quality improvement projects and embrace learning opportunities that we may not consider to be part of our everyday work. Through doing so, we can learn from other specialities and shape our own services, based on what has worked for patients and their families elsewhere. I am of the opinion that a short, simple tool such as IPOS is easy enough to complete for most patients and should be used more frequently in all of our healthcare services, from the point of diagnosis where necessary. If IPOS was to be introduced at an earlier stage and across a wider area, our service could be improved not only for our patients, but also for ourselves, as healthcare professionals. Armed with the knowledge of the most troublesome problems with which our patients are struggling, earlier intervention can be achieved, thereby facilitating patient centred care of the highest quality. Would this not, after all, be how we would wish to be treated if we found ourselves in this distressing situation?

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