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To Whom it may Concern:

Thank you for taking the time to review our journal submission. Our study has been developed from an initial case note review and into the development of an audit at the community level, over several years. The area of focus is on the assessment and diagnosis of depression in patients receiving palliative care. Please let us know if you have any further questions.

Kind Regards,

Ana & Becky

Diagnosing Levels of Distress in Specialist Palliative Care

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Abstract

As palliative care services swiftly expand to meet the increasing demands of society with its ageing population and the advances in medicine that prolong life, so does the need for the development and use of practical, accurate, and standardised assessment tools. We would assert that one of the most complex challenges facing health care professionals working in palliative care is the identification and implementation of best-practice methods in the diagnosis of depression in their patients. Research was conducted in several planned stages, and our actions investigated through the implementation of an audit cycle. In observing the effect of our actions at each stage of the cycle, we were growing a scaffolding of knowledge. We continuously incorporate findings into subsequent stages of the research. Through incorporation of standardised tools and methods for the assessment of depression in our patients, we were able to increases staff knowledge and improve patient care.

Keywords

palliative care, community, depression, diagnosis, specialist, end-of-life

Word Count: 3,349 characters

Diagnosing Levels of Distress in Specialist Palliative Care

> When all you have in your hand is a hammer, everything becomes a nail.
>
> Gregory Bateson

Introduction

As palliative care services swiftly expand to meet the increasing demands of society with its ageing population and the advances in medicine that prolong life, so does the need for the development and use of practical, accurate, and standardised assessment tools. We would assert that one of the most complex challenges facing health care professionals working in palliative care is the identification and implementation of best-practice methods in the diagnosis of depression in their patients. Depression is the most studied mental health disorder in palliative care (Wasteson et al., 2009). However, no consensus exists on precisely which of the 106 identified tools designed to diagnosis depression should be implemented (Wasteson et al., 2009). Without clearly identified means for best practice it is left to the individual health care professional to sift through the available literature, which contains a high concentration of polarising contradictions. Recommendations in the literature are often not approved for patients receiving palliative care, or limited to studies undertaken in specific care settings that are not applicable to a broader spectrum of care environments. When best-practice methods are not implemented in daily routines, it results in lowering the quality and efficacy of the care being given to patients.

To further complicate matters, patients enrolled in palliative care services are likely to be experiencing a vast array of both chronic and acute physical symptoms which can mask or result in false positives in the diagnosis of depression (Massie & Holland, 1990). This makes it difficult to incorporate classically used assessment tools. For example, four of the nine DSM-IV criteria (American Psychiatric Association, 1994) required for a diagnosis of clinical depression are somatically-based. The criteria also explicitly states, " Do not include symptoms that are clearly due to a general medical condition (American Psychiatric Association, 1994).

Above all, undiagnosed depression has the potential to not only affect the psychological and physical well-being of the patient, but their carers as well. Depression has also been found to have the ability to exacerbate pain and other physical symptoms, which may limit the patient's ability to emotionally connect and interact with family members (Massie, 1992). It also dramatically increases the risk of suicide and hastened death (Chochinov et al., 1995).

When a patient experiences depression, the likelihood their partner will also face emotional challenges significantly rises (Harrison et al., 1995). Therapeutic work with people near the end of their lives is uniquely challenging, in that the outcome is unchanging (Draper, 2009). Kellehear (1990) asserts that for the patient, a "good death" may include feeling they are psychologically equipped for death with control in how the death occurs and a voice that informs the multidisciplinary team to create a bespoke care package. To increase the likelihood of a "good death" occurring, crucial steps must be taken. Health care professionals can help increase the likelihood of a good death occurring, by ensuring the use of evaluated best practice methods when assessing a patient's mental health.

Methodology

To better understand what best practice looks like, we needed to bring theory and practice together and gather information which gives us a bench mark from which we can measure against and then develop an action research process through an audit cycle.

Action research has been described by its creator, Lewin (Adelman, 1993) as a spiral of steps, each of which is composed of a circle of planning, action and fact finding about the result of the action.

Our research was conducted in several planned stages, and our actions investigated through the implementation of an audit cycle. In observing the effect of our actions at each stage of the cycle, we were growing a scaffolding of knowledge which allowed us to continuously incorporate findings into subsequent stages of the research.

Method

The action research cycles were as follows:

1) Audit looking at current practice within the service and literature review.

2) Review of findings and actions agreed for future investigation.

3) 2nd audit looking at the result of our actions

4) Same as 2.

5) 3rd audit looking at the result of our actions

6) Same as 2.

7) 4th audit looking at the result of our actions

8) Same as 2.

1) Audit looking at current practice within the service and literature review.

In order to identify and incorporate the best methods for assessing distress in a community palliative care setting, a two part audit was initially conducted. An audit involves comparing current practices of an institution with those most empirically and professionally supported to ensure the presence of evidence-based practice ("Healthcare Improvement Scotland", 2007). Audits are used frequently in health care as a method of clinical governance to improve current practices and ensure the highest level of care quality ("Healthcare Improvement Scotland", 2007). With such low levels of standardisation available empirically, it was predicted that the clinical practices of the specialist palliative care team would mirror the inconsistencies present in the existing literature. Therefore, the hypothesis was that depression occurring within patients receiving palliative care in the community would be under diagnosed.

The primary audit occurred between April and August 2011. The first phase was a systematically-based literature review used to identify available assessment tools, and establish evidence-based methods for evaluating mood in a population receiving specialist palliative care. During the second phase, a retrospective case note review was carried out, containing a stratified selection of case notes maintained by a specialist palliative nursing team.

Potential psychometric tools were screened through the incorporation of a systematic literature review, consisted of empirical articles being screened for relevance, quality, and the use of strict inclusion and exclusion criteria. The Critical Appraisal Skills Programme (CASP) was consulted to analyse the quality of articles (Public Health Resource Unit, 2006). After eliminating repeated papers, irrelevant, and inadequate quality; 23 of the original 253 were selected for a comprehensive review. Within the 23 studies selected, 11 were designed to assess depression and 12 for QOL. After analysis, three tools were selected as being the strongest based on: empirical support for evidence-based practice methods, strength of the studies, and sensitivity to a community, palliative care setting. The tools selected to create a coding system in order to analyse the case notes were the WHOQOL-100 (The World Health Organisation), the Brief Edinburgh Depression Scale (Lloyd-Williams, Shiels, & Dowrick, 2007), and the DSM-IV (American Psychiatric Association, 1994) criteria for depression, with the removal of somatic symptoms (American Psychiatric Association, 1994; Periyakoil & Hallenbeck, 2002).

The second phase of the audit was case notes which were analysed to determine how depression was being assessed and recorded by the nurses. The sample consisted of the twenty patients, representing 10% of the registered patients in that time frame. Case notes were stratified by age, gender, and diagnosis. Based upon the results of the literature review, content analysis of the case notes was applied using a coding scheme developed from the psychometric tools identified as being empirically-supported, as well as most fitting and applicable for palliative patients in a community setting. The chosen instruments were used in the examination of case notes. The three instruments were coalesced to create two individual coding schemes. The first was used to determine which factors of quality of life were most commonly affected in the sample, and how often psychological mood was recorded by the specialist nurses.

A second coding scheme was also created to enable occurrences of depression and mood disturbances to be derived from the data . It incorporated the DSM-IV (American Psychiatric Association, 1994) criteria for depression with removal of any somatic criteria, and replaced with cognitive and observable signs of depression (Noorani & Montagnini, 2007). To evaluate the depression on an immediate basis, question derived content from the Brief Edinburgh Depression Scale ((Lloyd-Williams, Shiels, & Dowrick, 2007) was gathered. Some of the criteria between the two tools overlapped, and repetitive content was eliminated. Direct content analysis was then carried out to assess the data.

2) Review of findings and actions agreed for future investigation.

The findings were reviewed and the next step of action agreed with the whole clinical team. That being the use of a measurement tool to identify distress.

3) 2nd audit looking at the result of our actions

The additional steps were taken forward as actions towards ongoing knowledge and subsequent audit cycles:

4 – 8) In seeking to increase standardisation and accuracy in assessing psychological distress within patients being managed by the specialist palliative care team, a further audit cycle was conducted. Building upon the findings of the initial pilot study, an opportunity was identified to implement greater use of evidence-based practice methods in the assessment of psychological well-being of the patients. The audit consisted of three additional phases, prompted by the findings from the initial study which evaluated the assessment process to identify depression in patients receiving palliative care. The study cycles implemented the use of the Distress Thermometer (DT) which is a validated and recognised tool to assess for distress with patients and family members in palliative care (Mitchell et al., 2007; Roth et al. ,1998; Gessler et al. , 2008; Zwahlem et al , 2008). The DT used was established by the National Comprehensive Network Guidelines® (NCCN®), for use with cancer patients.

The DT was also validated for use by the psychology group at the Mount Vernon Cancer Network (MVCN), and therefore the tool of choice in respect to distress screening were the specialist palliative care service is based. In 2006, the MVCN published the “Framework for the Assessment and Management of the Psychological Well-Being of Adults with a Cancer or Palliative Diagnosis” (MVCN, 2006) which was drawn from NICE Guidance (NICE). It sought to improve care by providing means for evidence-based practice to occur. Mitchell (2007) found that ultra-short methods as a screening process are best at ruling out depression, anxiety or distress with an accuracy of 85 – 95%. Mitchell et al. (2008) also found that clinicians prefer distress management measurement tools and that only a third of cancer clinicians would be prepared to use identifying instruments in routine care.

Participants

All new referrals in a given time period to the NHS specialist palliative care team (West Hertfordshire) were initially eligible as participants in the audit. At the time the second cycle of the audit was conducted, there were 137 new referrals to the service. Twenty-three DT were completed, despite the fact that all new referrals were in the inclusion criteria. The inclusion criteria also consisted of the patient’s cognitive ability to complete a DT, and willingness to answer questions on the DT as part of their care plan. Exclusion from participation in the audit was based upon mental and psychical capacity, such as dementia and physical symptoms at the end of life.

Ethical Considerations

According to NHS Governance policies, all individuals pre-consent to their information being used for potential research when registering with the NHS (NHS Department of Health, 2011). The NHS upholds strict standards in data management that ensure patient anonymity is guarded and maintained. These standards were upheld by the team members collecting and processing the data, by use of data encryption and exclusion of individual identifiable details. The goal of the audit centres on improvement in assessment and appropriate referral, rather than the individual health information of the patient. Therefore, Information was analysed en masse, and not on an individual case-by-case basis.

Permission was obtained from the National Comprehensive Cancer Network® (NCCN®) for the reproduction of the DT Screening Tool Figure (DIS-A) for use of the DT according to their **NCCN Clinical Practice Guidelines in Oncology for Distress Management V.2.2013.**

To address the findings of the original audit, a pilot was agreed to undertake to do the DT on new referrals to the given geographical area for one month.

The primary purpose was to screen for distress and the secondary purpose was to investigate the reticence of staff to use a diagnostic tool in their general clinical assessment of patients.

Procedure

Team members agreed to complete a DT. Timing of DT administration was based on their professional judgement and individual patient needs. No guidance was given as to when to use the DT with patients. The patient was asked for consent to use the DT as part of their care package. The results were recorded in the case notes, and information collected was dispersed to the team's psychotherapist. The results of patients scoring a 6 or above were consulted by level IV personnel, and then discussed a strategy of psychological support.

The second phase of the audit occurred between 1st February 2012 and 1st March 2012. At that time, there were 137 new referrals to the service. Staff worked towards completion of a DT within two clinical sessions at the time of assessment.

The third audit cycle took place between 1st May 2012 and 31st of June 2012. It included the Heart Failure team, in addition to two specialist palliative care localities.

The fourth audit cycle took place between the 1st March and the 31st March 2013. It included all the previous services, as well as a local Hospice.

Results

Table 1 summarizes the findings and recommendations for each cycle of the audit.

Table 1

Findings delineated by audit cycle

Cycle	Findings	Recommendations
1	55% of patients display depression characteristics. 25% were referred for psychological support. 35% of referrals to the team were for psychological support. 0% of patients were scored on a relevant tool to discern psychological distress.	**Identify a tool for assessment of depression.** **Record supervision and consultation in case notes and S1 as a form of MDT working re psychological care.**
2	17% of patients had a Distress	**Re-run audit**

	Thermometer scoring.	**All staff to complete a Distress Thermometer to identify psychological needs within two clinical sessions.** **Re-train all staff in the use of the Distress Thermometer.** **All patients who score 6 – 10 on the DT to be discussed with a level 4 clinician.** **The North side of the team and Heart Failure Service join the use of the Distress Thermometer and audit process.**
3	44.4% of patients had a Distress Thermometer score completed. Some patients were assessed as being inappropriate to the service and therefore discharged without formal assessment. 42% of referrals from the West side of the team were referred for psychological support. 0% referrals were made to psychology in the North side of the team. Some patients were offered a referral to psychology services but refused.	**Implement the use of the Distress Thermometer and look to gain 100% compliance.** **All staff work to complete a Distress Thermometer within two clinical sessions as a mandatory action.** **All patients who score 6 or above to be discussed with a level 3/4 clinician present.** **Patients scoring 4 or 5 are to be discussed in clinical supervision.** **Develop a referral pathway for the Heart Failure Service.**

4	**82% of DT's were attempted and that 55% of DT's were fully completed.** **Resulted referrals of those who had a DT completed for** **further psychological assessment was 17 (21%).** **6% were referred to a level 3 worker at the Peace Hospice** **12% were referred to the level 4 worker in the north** **35% were referred to the level 4 worker in the west.** **Because of the DT score – 47% were consultations with a level 4 and level two interventions agreed in the West.** **All 6 DT's from IPU were taken to the clinical meeting at the Peace Hospice**	**Continue to promote the use and look to gain 100% compliance.** **To continue to integrate the DT completion within two clinical** **sessions with a patient as part of the holistic assessment and this continue to be mandatory.** **Review and audit the DT in 6 months time.** **To continue to use the framework in which:** **All DT's scored at 6 – 10 are discussed at an MDT, supervision or consultation with a level 3/4 clinician.** **Pts scoring 4 – 5 is discussed in Supervision.** **Continue to use referral pathway for HFS and agree clinical** **Psychological input, via MDT for all patients.** **Promote and facilitate the use of the DT in other agencies to ensure patient safety, equal access and identification of** **Psychological needs and commonality in practice to aid coordination.**

Discussion

The findings of the 1st audit identified that clinicians did not hold accurate beliefs about their ability to identify psychological distress. This enabled conversations to emerge where the introduction of a tool was seen as something that needed to be explored.

The second audit found that there was still a reticence to use a tool, and the team agreed to implement measurers that were mandatory. The next audit cycle showed that the team who had most used the tool had a higher level of completing a DT and this was amplified in the 4th audit. The implication of this suggests that the staff reticence was diminishing and their understanding of the use of such a tool changing as part of the process from which discussion informed practice and lead to further investigation. This finding was replicated in further audit cycles, amplifying that an action research methodology supports change in the involvement of clinicians as part of the learning process. It also supports the evidencing, through participation, of best practice.

Using this methodology, invited participation to find solutions to the dilemma helped shape an even playing field, from a power differential perspective, between the different professions represented in the multi-disciplinary team. In not having the answers and implementing solution ownership through exploration and application the success of what was being achieved belonged to all in equal measure.

The team explored after each audit cycle the affect of implementation of a tool that identified distress for patients. This was in response to the base line audit that showed that they couldn’t rely on their intuitive to identify patient’s distress. The process clarified the psychotherapeutic role within the team and allowed for changes to occur in the use of clinical supervision. A major change was that they started to bring their case load to each session and we were able to identify strategies for those scoring below 6 and referral ideas for those above. This function also gave birth to a pathway that functioned in providing a central referral point for team members, an identification process from which clinicians could act and a common language that fitted across services and organisations. Despite this, due to the disparity between commissioning and availability of psychotherapeutic clinicians, the right level of support was not always available according to identified need.

The result from this work is the potential for consistent and better distributed services, which goes on being explored in the continuum of the ongoing action research process. In seeking to implement the recommendations by the MVCN and its original findings from the 1st audit, it was established that psychometric tools and criteria would be uniform across the practices. A pattern of increased usage of the DT as part of the assessment process was established each cycle, and is likely to steadily increase as the tool continues to be introduced and used.

This research is never ending. We are currently taking further steps to support other organisations, who work in a diverse way to implement the use of this tool to identify distress. These organisations are divers and include a hospice at home team, a GP practice and a nursing home. All are engaged in delivering palliative care and are keen to find ways in which they can not only identify the distress level being experienced, but to be able to access psychological support and supervision as required.

Conclusion

The management of change is a complex process, which often falters because of power differentials which are constraining to the inherent knowledge held by each professional group.

Action research is not only a way of conducting investigation, but a clinical tool that values difference, enters into dialogue and uses a feedback process from which actions taken can be evaluated, modified and support the increase in supporting evidence that shapes the basis of practice. It reduces the likelihood of slavish adherence to certainty in practice and forms a canopy of safety from which new understanding and practice can emerge.

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