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Staff perceptions of the use of the patient dignity inventory (PDI) in a Welsh palliative care service

April Lloyd^{1,2}, Daniel R. Stubbings^{2,3}, Joseph L. Davies ³

¹Cardiff University, Cardiff, Wales, ²Cwm Taff Morgannwg Cancer and Palliative Care Psychological Service, National Health Service, ³Cardiff Metropolitan University, Cardiff, Wales

Background: Dignity-related psychological distress can often be unidentified and untreated within palliative care services. The Patient Dignity Inventory (PDI) measures the factors associated with an individual's sense of dignity-related psychological distress. This study aimed to obtain staff members' perspectives on the feasibility of utilising the PDI in a palliative care service in Wales.

Method: Seven experienced staff members were recruited from a Welsh Cancer and Palliative Care service. A thematic analysis of data collected via semi-structured interviews revealed three key themes and nine associated subthemes.

Main findings: The first theme was 'Positive Outcomes and Uses', which included three subthemes: Supporting Staff in their Clinical Practice, Patient Empowerment and Flexibility of Use. The second theme was 'Staff Concerns' that had two subthemes: Causing Distress and Confidence in Existential Conversations. The third theme was 'Barriers and Considerations to Implementation', which included Cultural Considerations, Staff Support and Length of the Measure.

Conclusions: The findings suggest that the PDI could be valuable to clinical staff in supporting the identification of dignity difficulties and/or distress among patients. However, steps should be taken to address barriers to successful implementation and increased staff training on the measure.

Key Words: Dignity, Distress, Palliative care, Patient dignity inventory, Cancer

Introduction

Dignity refers to a person's sense of worth and self-respect and is an integral aspect of well-being¹. There is evidence to suggest that the impairment of dignity can negatively impact a person's health journey² and increase feelings of hopelessness and worthlessness³. These issues are particularly typified in the context of palliative care⁴. Service users in palliative care can be faced with numerous physical, psychological, existential, and spiritual challenges that can undermine their sense of dignity⁵. This ultimately exacerbates the amelioration of distress and suffering in terminally ill individuals⁶.

Specialist palliative care services play an important role in the end stages of life, with advanced care planning, and pain and symptom management being core service interventions that improve patient outcomes⁷. Staff within specialist palliative services endeavour to reduce psychological distress and provide dignity-conserving care. A variety of healthcare policies have been

developed and implemented to ensure that people are treated in a way that preserves their dignity and respect^{8, 9}. Despite this, psychological distress is not likely to be reduced for terminally ill individuals in the context of typical palliative care interventions¹⁰. This highlights the importance of timely identification and exploration of the nature of psychological distress, to provide effective psychological intervention.

Psychological distress in the palliative population is often unidentified and subsequently untreated; significantly impacting the individual and their family¹¹. Dignity-related distress is a significant problem for individuals in the palliative population¹² and the loss of dignity is associated with greater experiences of psychological distress⁴. Higher rates of psychological distress are found in individuals in the advanced stages of metastatic cancer, with around 10–15% of patients requiring specialist psychological or psychiatric intervention¹³. The source of dignity-related psychological distress varies among palliative populations. Cancer patients report higher levels of distress associated with physical and psychological symptoms, whereas individuals with Motor Neuron Disease

*Correspondence to: April Lloyd, Cardiff University, Cardiff, Wales; Cwm Taff Morgannwg Cancer and Palliative Care Psychological Service, National Health Service. Email: LloydAE4@cardiff.ac.uk

(MND) report increased distress associated with feeling like a burden to others, and/or being unable to fulfil important roles⁵. Understanding the source of distress provides the opportunity to increase understanding of the individual's experience among the care team and subsequently inform how best to meet their palliative care needs.

The assessment of dignity-related distress in palliative care can be challenging due to a lack of awareness and skills among clinicians to differentiate distress from appropriate sadness, and the normalisation of distress by patients in response to their diagnosis¹⁴. Early detection and understanding the cause of distress are important as individuals with as few as weeks or months to live can benefit from psychotherapy¹⁵ or pharmaceutical intervention¹⁶. There is significant variability in how psychological distress is managed within palliative care services and research highlights the importance of establishing best practices for the screening and treatment of psychological distress¹⁷. The use of tools to measure distress within palliative care services has been shown to aid the identification and treatment of dignity-related distress and identify those who would benefit from specialist psychological intervention¹⁸.

The Patient Dignity Inventory (PDI)⁴ is a validated instrument developed from the empirical model of dignity in palliative care, which aims to identify the various sources of dignity-related distress in palliative patients¹⁸. The PDI has been validated and used to assess dignity-related distress in critical care¹⁹ and palliative care settings¹⁸ and has been translated and validated cross-culturally in languages such as Italian, Czech, Mandarin, and Korean^{20–23}. In one study, specialist palliative care clinicians reported that using the PDI supported the detection of previously unknown concerns in 80% of cases and its value was also noted when working with individuals who have difficulty expressing their emotions²⁴. The use of the PDI has also been reported among healthcare professionals to lead to opportunities for profound and meaningful conversations regarding the individual's distress and illness²⁵.

Whilst the value of the measure has been explored among palliative care staff in Canada and Spain^{24, 25}, no studies have investigated staff perceptions of strengths and possible barriers and/or considerations to the implementation of the PDI within palliative care services in Wales. Considering staff perspectives of the measure prior to implementation is important, as implementing a measure that would not be suitable for service users would be unethical, and effective implementation would rely on the motivation and willingness of staff to utilise the measure in practice.

Methods

Participants

The current study was approved by Cwm Taf Morgannwg University Health Board as a service evaluation (approval number: CT/1784/22/23). The inclusion criteria for the project included: current employment within the specialist palliative care service in a patient-facing role, a willingness to provide written consent, and a willingness to undertake a recorded interview with the lead researcher. Seven members of the palliative care staff team agreed to take part in an interview. This included one Therapy Technician, one Senior House Officer (SHO), four Clinical Nurse Specialists (CNS), and one Specialty Doctor in Palliative Medicine. The number of years of experience working in palliative care settings varied among participants. One member of staff had less than two years of palliative care experience, two staff members had nine years of palliative care experience and four staff members had between 12 & 17 years of palliative care experience.

Design

A qualitative semi-structured interview design was used to collect data within the palliative care service, allowing the exploration of the needs of this specific service. The use of a semi-structured interview yielded opportunities to obtain detailed information about staff members' subjective perspectives of the PDI and provided flexibility to explore these perspectives further during the interviews.

Materials

The patient dignity inventory

A paper copy of the Patient Dignity Inventory¹⁸ was provided to participants prior to the interview. The Patient Dignity Inventory is a 25-item questionnaire exploring factors relating to a person's sense of dignity. This includes physical, functional, psychosocial, existential, and spiritual concerns. Responses are recorded on a Likert scale of 1 'Not a problem at all' to 5 'An overwhelming problem'. The Cronbach's coefficient alpha for the PDI ($\alpha = .93$) and the test-retest reliability are good ($r = .85$). A five-factor model including the subscales of Symptom Distress, Existential Distress, Dependency, Peace of Mind and Social Support account for 58% of the variance in the data¹⁸.

Procedure

Staff were approached by the lead researcher and provided with verbal information about the project. Those who expressed an interest were provided with further information via an information sheet and consent form. Staff members who agreed to participate were contacted to arrange a suitable time to

conduct the interview with the lead researcher. Before the interview, participants were reminded that the interview would be recorded using a dictaphone and that their participation was voluntary. Participants were informed that they could terminate the interview at any time but that their information could not be withdrawn after the interview, as the information would be anonymised, and could therefore not be identified as theirs to remove it. Following the completion of the consent form the lead researcher began recording and the interview took place. At the end of the interview, participants were thanked for their participation and the interview was transcribed. Reflexive semantic thematic analysis was conducted and the six-step procedure by Braun and Clarke²⁶ was followed.

Results

Three key themes were identified through thematic analysis. These included ‘Positive Outcomes and Uses’, ‘Staff Concerns’ and ‘Barriers and Considerations to Implementation’. Each theme had several sub-themes. These are highlighted in Table 1 and outlined in greater detail below.

Positive outcomes and uses

All staff members identified positive uses and outcomes that may come because of using the PDI in clinical practice. The three sub-categories identified within this key theme include: ‘Supporting Staff in their Clinical Practice’, ‘Patient Empowerment’ and ‘Flexibility of Use’. Many participant responses referenced the various ways that the use of the PDI could support staff members in their clinical practice and interactions with patients. Respondents felt that using the PDI would provide them with opportunities to identify various causes of distress that may have previously been unknown to the care team:

I think it would help us to identify how people are really feeling ... sometimes we think we are

doing A, B and C to help them, but you can see something else is underlying ... I think it would help identify those problems.

Participants also reflected on the possibility that the PDI could support staff to initiate and engage in meaningful conversations that are typically undertaken once a positive relationship had been built with the patient over time; therefore, allowing these conversations to be facilitated earlier in the patient’s care journey: ‘I think it opens the door for some of those difficult conversations earlier’.

Others felt that the PDI provides a focus and helpful structure to guide questioning and obtain useful information from the patient was also noted by many of the respondents: ‘My initial thoughts were that it is nice to have structure or something that could guide questioning’.

Patient empowerment

All of the respondents noted the value that the PDI could offer in terms of empowering and supporting patients to identify, acknowledge, and reflect on their own distress and experiences: ‘I think it’s about generally getting people to think about ... can I do this for myself, do I have problems with that? It is a bit more sensitive, rather than asking directly if that makes sense’.

Some of the staff members commented on how the PDI provides patients with a choice about how to disclose sensitive information. The opportunity to disclose information non-verbally was noted, as well as the option to elaborate on their experiences further during discussions with the care team whilst, or after completing the questionnaire: ‘Patients could choose to elaborate on their responses or acknowledge these difficulties non-verbally’.

Flexibility of use

All the staff members noted that the measure could be helpful to a variety of staff across various palliative care settings throughout the patient’s care journey, irrespective of years of experience working in the field. However, four of the staff members noted that the measure could be specifically helpful for junior staff who are new to working in palliative care to provide a structure to their questioning: ‘I think it would be good for all staff to use’, ‘For staff who have perhaps not got that much experience, I think it would be a really useful tool’.

Staff members felt that the measure could also be useful across all palliative care settings including out-patient, community, and acute settings. Whilst all of the respondents felt that the measure could be helpful during any stage of the individual’s illness, six of the staff members noted that it may be particularly useful during the earlier stages of illness: ‘I think

Table 1. Study themes and sub-themes.

Theme	Sub-theme
Positive outcomes and uses	Supporting staff in their clinical practice Patient empowerment Flexibility of use
Staff concerns	Causing distress Confidence in existential conversations
Barriers and considerations to implementation	Cultural considerations Staff support Length of the measure Obtaining a true picture

this could help people to have these conversations earlier on... sometimes it's important for these things to be talked about earlier on'.

Two of the staff members also referred to other possible uses of the questionnaire. The value of utilising the tool to monitor an individual's distress and well-being over time, as well as review the effectiveness of staff interventions was noted: 'If you did one of these at the earliest time that you met the patient and then again to review the effectiveness of care, I think this would be helpful'.

Staff concerns

Many of the respondents shared concerns about evoking distress in patients whilst completing the measure, as well as concerns about responding to, and facilitating conversations that are existential in nature. Sub-themes are labelled 'Causing Distress' and 'Confidence in Existential Conversations'.

Causing distress

Six of the staff members shared that they had some concerns about evoking distress in patients during questioning by drawing attention to possibly upsetting or distressing topics. Staff also shared feelings of wanting to protect the patient from experiencing any further distress: 'It might distress them further and leave them with lots of other questions which they weren't already thinking about'.

Confidence in existential conversations

Six of the staff members shared that they would lack confidence in managing responses and conversations that are existentially challenging, such as questions relating to the meaning of life, the purpose of one's life, and the nature of reality: 'I think as healthcare professionals we would probably struggle with the deeper meaningful questions but that is probably just a personal feeling, you know like whether life has meaning or purpose... but they are important questions'.

Barriers and considerations to implementation

The third key theme emerging from the data revealed various barriers and considerations that could impact the effective implementation and use of the measure in clinical practice. The four sub-categories identified within this theme have been labelled 'Cultural Considerations', 'Staff Support', 'Length of the Measure' and 'Obtaining a True Picture'.

Cultural considerations

Five staff members referred to the difficulties experienced by some of the patients in the healthboard's population, such as difficulties with reading, writing, and understanding information. Respondents noted the importance of considering an individual's literacy

skills prior to the administration of the measure, to avoid a negative or disempowering experience for the individual: 'So, I work in quite a poor area with lots of literacy issues, and I can think of a few patients over last couple of months who have had literacy issues, that couldn't complete it by themselves'.

Three staff members commented on the possibility that individuals could interpret questions differently based on their understanding and literacy skills, and their own personal experiences and culture: 'I think with some of the questions, I'm not sure my patient group would understand ...'.

Staff support

All the staff members felt that it would be helpful to receive support around using the measure in their clinical practice. Five of the staff members noted that they would like to receive training on the administration of the measure and managing patients' responses to the questions; particularly around managing difficult conversations: 'Yeah, so I'd want prior training on maybe how to navigate some of the more difficult conversations that come up in the PDI'.

All the respondents also felt that it would be useful to have an additional document with information for staff to signpost or refer patients to relevant services (e.g. Occupational Therapy, Counselling/Psychology Services), based on their responses to questions in the measure: 'What can I do with the answers that I have been given? It would be useful to have some sort of idea of signposting information sheet'.

Two of the staff members felt it would be useful for junior staff members or those with less experience in palliative care to shadow other staff members administering the measure, prior to undertaking the measure independently: 'Maybe coupling up or shadowing another member of staff could help ...'.

Length of the measure

Participants also felt that the measure was too long, noting that completing all the questions may be too much for patients to complete in one session: 'I think half of that probably would be enough in one session, you know, you could always re-look at that in a different session'.

Three of the staff members commented that a shorter version of the measure would be helpful, and wondered whether many of the questions could be grouped together to reduce the likelihood of patients feeling overwhelmed: 'To keep it as simple as possible, I wonder if it could be condensed a bit'.

Obtaining a true picture

Most of the staff members commented on the importance of creating an environment where patients feel able to answer the questions honestly, so that a true picture of their current difficulties and distress can

be obtained. Five of the respondents felt that completing the measure with a family member present could impact on patients' responses, therefore impacting the results and subsequent understanding developed by the care team: 'If they do it with a family member maybe you would get a totally different outcome, often people hide their feelings from their family'.

Three of the staff members felt allowing patients to have time to complete the PDI on an individual basis would provide time for the person to reflect on their distress and difficulties and would facilitate more truthful responses to the questions: 'Perhaps they might just want to do it on their own, they don't want to be asked those questions with family, they may feel better about doing it privately'.

Discussion

The aim of the current study was to explore staff perspectives on the use of the PDI in a Welsh palliative care service to support the identification and subsequent treatment of dignity-related psychological distress among patients. Staff members predicted various positive outcomes of using the measure in clinical practice. Respondents felt that using the measure could provide opportunities for staff to identify difficulties that were previously unknown to the team, as well as facilitate difficult conversations to take place earlier in the individual's care journey. This is an important benefit to consider as effective management of emotional difficulties earlier on in the patient's illness has been shown to promote patients' understanding and adjustment to their illness; subsequently improving the quality of end-of-life care²⁷. Staff members also felt that the measure could be used flexibly across various professions to empower patients and to share their distress or difficulties in a way that feels most comfortable for them (e.g. verbally/non-verbally). These findings support the claims of Ryan et al.²⁸ that the use of screening tools to detect psychological distress can address barriers to the disclosure of psychological concerns among patients and support the recognition and management of an individual's distress.

Despite the positive potential of the measure, analysis of the data found that respondents also had concerns about causing distress for patients during the administration of the measure. Concerns about staff members' confidence in managing existentially challenging conversations and situations arose. Respondents felt that receiving training on how to manage patients' responses and facilitate difficult conversations would be helpful prior to implementation in the service. Sand et al.²⁹ (2018) demonstrated the importance of providing training on supporting

oneself and others during existential crises in improving perceived knowledge, preparedness, and competence among palliative care staff during existentially challenging situations.

The data derived from the current study also revealed the importance of having an awareness of historical, local, societal, and contextual factors that may impact a patient's ability to fully engage with completing the PDI. Poor literacy skills can be found among 15% of the population over 55 years old in Wales³⁰. Therefore, it is important to consider how patients can be supported to complete the measure in order to provide equity in the service and prevent any patients from being disadvantaged. The length of the measure was also considered to be too long and possibly overwhelming for patients to complete in one session. Respondents felt that a shorter version of the measure would be more helpful. This is consistent with the views of other clinicians who felt that two or three simple questions or a short, validated measure to detect distress, would be the most ideal in practice³¹.

Limitations, strengths and future research

Before interpreting our findings, it is important to consider the study limitations. Given that there was only a limited proportion of the palliative care staff team participated in the current study, there may be limitations in the generalisability of the study findings. A further limitation of the study is that the participants did not administer the measure prior to providing their perspectives during interview. The findings may have differed had staff members had first-hand experience of undertaking the measure, prior to interview. Future research might include a greater number of participants and may explore perceptions of staff who have utilised the measure prior to interview as a comparison group with those that have not used the measure.

Despite these limitations, the current study finds strength in its effort to consider the needs of the service, patients, and staff members to ensure that any implementation of a measure to assess psychological distress is applicable and fit for purpose. Overall feedback from participants in the project was positive, in that they felt valued, and appreciated the opportunity to provide their perspective prior to the implementation of the measure in the service. The key themes and findings emerging from the data suggest that the PDI would be valuable to implement within the service, but the following suggestions are made to increase the chances of success:

- Provide training to improve staff confidence in how to administer the measure, facilitate conversations that are existentially challenging, and improve

awareness of any cultural considerations that need to be made for patients in the service.

- Provide a signposting document detailing appropriate services that could meet the needs of any difficulties that arise during the completion of the measure.
- Facilitate opportunities for junior members of staff to shadow more experienced staff administering the measure prior to using the PDI independently if needed.

Future research that develops and validates a shorter version of the PDI may also be helpful. It would also be valuable to consider service user perspective on the measure, as well as obtain staff perceptions after they have administered the measure. In conclusion, this project is the first step in providing better assessment of patient dignity needs in palliative care. This measure appears useful to both staff and patients but should be introduced to services in a way that takes on board the above suggestions.

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ORCID

Joseph L. Davies  <http://orcid.org/0000-0002-6011-8591>

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