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Research Article

ROLE OF NURSE IN PALLIATIVE CARE FOR PATIENT WITH DISABILITIES

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Abstract:

The availability of nurses and their overall health expertise govern their position in palliative care. Acting as a coordinator and liaison between patient and family, other health professions, and different healthcare services is a prominent, but not always valued, role for nurses. The goal of this review is to create a detailed account of the district nurse's role in providing palliative care. Papers in English reporting on aspects of the district nurse role in palliative care provision published up to 2022 were included. We searched electronic databases (Ovid Medline, Cinnahl, British Nursing Index, Embase, PsycINFO, and EBM reviews), as well as citation tracking and grey literature. This synthesis contains little that sheds light on the outcomes of care or explicitly guides practice. District nurses clearly articulate what they believe is important, but research in this area is limited and requires a renaissance to examine what is important: specifically, what district nurses do in practice; what patients and family carers think about what they do and do not do; and how district nurses can improve care outcomes.

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INTRODUCTION:

While death is a natural part of life, it is frequently treated as an illness. As a result, many people die alone and in pain in hospitals [1]. Palliative care is primarily concerned with anticipating, preventing, diagnosing, and treating symptoms experienced by patients suffering from a serious or life-threatening illness, as well as assisting patients and their families in making medically significant decisions [2]. Regardless of diagnosis, the goal of palliative care is to improve the patient's and family's quality of life. Although palliative care, unlike hospice care, is not prognostic, as death approaches, the role of palliative care intensifies and focuses on aggressive symptom management and psychosocial support [2].

Palliative care and hospice care are terms that are sometimes used interchangeably. Hospice care, according to the National Quality Forum, is a service delivery system that provides palliative care/medicine when the life expectancy is 6 months or less and curative or life-prolonging therapy is no longer indicated [3]. As a result, it is critical to distinguish that, while hospice provides palliative care, palliative care is not hospice.

Nurses encounter patients with life-threatening illnesses in all healthcare settings. This necessitates palliative care knowledge and expertise wherever nurses work in the health system. Cicely Saunders [4], the founder of the modern Hospice movement, emphasised the importance of skilled and experienced nursing in the management of terminal malignant disease. Palliative care, which is based on the modern Hospice philosophy movement, provides guidelines for the care of seriously ill and dying patients to improve patients' and their families' quality of life. The approach is multidisciplinary in order to address the complexities of patients' and relatives' needs. According to the World Health Organisation [5,] a major barrier to improving care is a lack of palliative care training and awareness among health professionals. The European Association for Palliative Care (EACP) [6] defines ten core competencies for health personnel, stating that all personnel require knowledge and competence in these areas, but at varying levels depending on their exposure to various dimensions of [6].

The aim of this narrative review was to address the importance and the role of nurse in palliative care for patient with disabilities.

DISCUSSION:

Patients nearing the end of their lives may experience severe symptoms such as physical, spiritual, and psychosocial distress. Palliative medicine's goal is to prevent and manage these symptoms while improving quality of life throughout the dying process [7]. Affordably controlling pain and other symptoms, avoiding prolongation of the dying process, achieving a sense of self-control, finding meaning in life, and relieving the care burdens of family and loved ones while strengthening and completing those same relationships are all important factors for seriously ill patients [8]. The symptom burden increases as death approaches, while the patient's and family's tolerance for physical and emotional stress decreases. Primary palliative care interventions should take precedence at this time, with a reduced emphasis on restorative care[8].

The district nurses' reliance on intuition or "experience" to assess psychological concerns may explain the lack of accuracy in symptom assessment reported in the literature, such as underestimating patients' quality of life and overestimating anxiety and depression [9]. Ewing et al [10] found that district nurses were significantly more likely to report anxiety and depression, and that district nurses rated patients' emotional symptoms as more severe than patients did. This may be due, in part, to the difficulties that district nurses face in carrying out their supportive role. Where district nurses did consider that patients may have unmet psychological needs, they attributed their unwillingness to elicit these to a lack of skills to deal with them, putting them in an ideological bind once more.

The assumption here appears to be that everyone reacts similarly to life-threatening events, despite evidence suggesting that people's responses are highly individualized [11]. Although reluctance to probe patients' concerns may have been due to general practitioners and district nurses attributing their own feelings to patients in some cases, previous research by Grande et al [11] revealed that general practitioners and district nurses were less likely to identify symptoms that they felt least competent to treat. Perhaps district nurses were hesitant to ask patients about psychological concerns because they felt ill-equipped to handle them, adding to their dilemma.

However, the district nurse's role in assisting patients during the early, often protracted stages of their cancer journey is less clear than their role at the end of life [12]. Palliative care is a subset of supportive care that describes the care of people who have no cure. In their most recent guidance, the National Institute for Clinical Excellence (NICE) listed the various

components of supportive care.⁵ These include providing information, managing symptoms, and providing psychological, spiritual, and social support. Meeting cancer patients' physical, psychological, and spiritual needs holistically is difficult and at the heart of supportive and palliative care [13]. Many palliative care patients have unmet psychological needs, which is not unique to the United Kingdom. It is also known that there is a misalignment between professionals' and patients' perceptions of need, with professionals exaggerating some symptoms while downplaying others. Although the NICE Supportive and Palliative Care Guidance emphasises district nurses' role in supporting cancer patients at home, little is known about what this entails and the skills district nurses need to meet patients' support needs [14].

Contact was essential for developing relationships with patients and carers before the time came for intimate care and death. The division of traditional district nursing work into health and social care [15,16] has resulted in district nurses providing far less social care and, at the end of life, far less basic nursing care than previously. This opportunity is provided by palliative care. The importance that district nurses place on providing palliative care and "getting to know" cancer patients by providing support in the early palliative phase backs up previous research both in the UK and elsewhere. Early contact and "knowing the patient" are thought to be associated with high-quality palliative care [17].

Such a shift may call into question what is considered to be unique to palliative care as opposed to basic care. Nonetheless, this shift may result in a greater emphasis on the patient's quality of life at an earlier stage of the disease's progression rather than just at the end of life, resulting in a more fluid transition through the various stages of the illness trajectory (from curative treatment to life-prolonging treatment and end-of-life care). As a result, regardless of where the patient is in the course of a severe disease, a palliative approach is required, though it is obviously especially important at the end of life. This review, on the other hand, is concerned with the WHO's definition of palliative care as an approach that improves the quality of life of patients dealing with the problems associated with life-threatening illness [18].

The focus of palliative care is on seriously ill and dying patients. Patients receiving palliative care can be found throughout the health-care system. Even though nurses are the largest group of healthcare professionals, there is a lack of understanding of their role in providing palliative care across institutions and their place of work in the healthcare system [19].

Because of the nurses' availability, they became natural points of contact for the patient and family, as well as other health professionals. As a result, nurses described themselves as service coordinators, aiming to provide care for patients and their families [20,21,22]. Nurses in Uganda, whether working in home care or in hospitals, described their role as "spiders in a web." Their work was distinguished by collaboration with other professionals as well as with the patient and his or her family. Being available and doing what was required naturally positioned the nurses as a hub for other services. According to Kaasalainen *et al.* [23], nurses in rural Australia described themselves as "jacks of all trades." Being a liaison and coordinator was thought to be important for continuity of care, and it was accomplished by developing relationships with other services. Without this opportunity, nurses would rarely be able to provide optimal care to dying patients. The nurses working in UK home care appeared as "gatekeepers" to services provided by other professionals in the study by Austin *et al.* [24]. The nurses described their palliative care provision in four Swedish municipalities as at times even mitigating the effect of multiple care providers and unclear responsibilities [25]. The study by King *et al.* [26] depicts the district nurse at the top of the tree, stating that "without her (the nurse), the entire world would collapse, and there is no one else who would pull it all together." In many ways, the nurse served as a coordinator and liaison in a complex health-care system. Nurses played critical roles in communication with all parties involved in the care coordination process. It was critical to maintain open lines of communication with the family and patients, as well as the team and, in particular, the doctors. The core values of the nurses' role in an Australian hospital, according to Kirby, Broom, and Good *et al.* [27], were alleviating suffering, maintaining dignity, and providing comfort care. These values influenced the nurse-patient conversations, which were critical components of being present for the patient. In the context of two acute hospitals and two hospices in Scotland, Johnston and Smith [28] discovered that nurses perceived their role as listening, facilitating communication, and providing information. Some studies revealed the importance of clarifying needs and preferences, while others emphasized the importance of uncovering the situation's demands concurrently. doing what is required in the field of palliative care, nurses performed a variety of tasks. These would be tasks identified and performed by nurses in the course of their work, as seen on acute wards and in home care across continents. Howell *et al.* discovered that nurses in home care performed a wide range of activities

within a framework of assessment, planning, intervention, and evaluation, ranging from the relatively routine to the complex. All of these activities frequently formed the nurses' day-to-day interactions with patients and family members [29]. According to Schaepe et al. [30], nurses' roles in home care in Uganda included providing physical, psychosocial, and spiritual care. Howell et al. [31] discovered that the nurses described all the activities as difficult to measure, and that some of them constituted "hidden work," or work that was not registered or documented but was still required for care.

The nurses described their ideal vision of palliative care for them to feel fulfilled in their roles. This vision reflected the nurses' individual competencies. Hopkinson et al. [32] discovered a strong personal ideal—the nurse's personal view of how to care for dying patients—in their study of nurses working on acute medical wards in the UK. According to the findings, nurses felt more at ease and satisfied in their work with dying patients if their experiences matched this personal ideal. The nurses' great solidarity and responsibility reported shed light on their dedication in palliative care, focusing on personalised and individualised care described in their findings the nurses' strong ambition and dedication to provide high-quality care to dying patients and relatives. The nurses' commitment to patients was also demonstrated by their willingness to continue working with patients and families even when relationships became difficult and other agencies sought to withdraw [28]. Kindness, warmth, compassion, and genuineness were important interpersonal skills and qualities for nurses. Another way to describe the nurses' role as dedicated and present was to open oneself to the other. Devik, Enmarker, and Hellzen's et al. [33] study discovered that being dedicated meant being open to the presence of the other. Being open meant experiencing the patients' lives, sensing their milieu, history, and context, as well as being open to the nurse's own existence and emotions. When caring for patients who moved them emotionally, the nurses revealed that they were put in an emotional situation in which they exposed themselves to the vulnerability of the patients and their families. Being involved and dedicated meant nurses were exposed to both joy and sorrows. Furthermore, studies from various contexts across continents revealed that nurses used non-traditional work methods and themselves as instruments to provide comfort care, with creativity and personal engagement [34].

Many specialty societies advocate for the use of palliative care as early as possible. The American Society of Clinical Oncology recommends early

integration of palliative care alongside oncology care for any patient with a high symptom burden or advanced disease [34]. The American College of Chest Physicians believes that palliative care for patients with "an acutely devastating or chronically progressive pulmonary or cardiac disease and his/her family should be an integral part of cardiopulmonary medicine." [35] According to the American Heart Association and the American Stroke Association, "palliative care should be integrated into the care of all patients with advanced cardiovascular disease and stroke at an early stage of the disease trajectory." [36] Nonetheless, despite these and other strong position statements advocating for early referral to palliative care, widespread adoption of this practice is slow.

Palliative care uses an interdisciplinary approach to meet the needs of patients, though the team structure varies, and palliative care delivery models vary greatly by geographic location and primary care focus (inpatient vs outpatient, cancer focus vs multimorbidity, and so on). The National Consensus Project for Quality Palliative Care has identified eight palliative care delivery domains that represent the ideal interdisciplinary team structure. To meet the patient's total needs, the physical, psychological, social, and spiritual components of patient care are addressed within the patient's unique cultural context. Palliative care teams' comprehensive assessments have been shown to identify unmet needs. The median number of symptoms identified by comprehensive assessment in heart failure patients [25,26]. Assessing symptoms that clinicians are ill-equipped to improve, such as body dysmorphism or financial distress, is also important because it provides a more complete picture of a patient's situation. Comprehensive symptom assessment fosters provider trust provides insight into patient struggles and assists clinicians in monitoring patients who are at higher risk of clinical depression or anxiety. Furthermore, palliative care informs patients and families about their illness trajectories and prognoses after carefully assessing patient preferences for medical disclosure [26].

CONCLUSION:

The role of the nurse necessitates knowledge and clinical experience in all core areas of nursing. As a result, nurses must be skilled in fundamental mental nursing to provide patients and families with individually tailored palliative care. To fulfil their role in palliative care, they must go beyond routines, trust intuitive feelings, and be guided by a sense of the situation, as well as possess professional and person-oriented competencies that are highly intertwined. Furthermore, the nurse's role encompasses three

distinct dimensions that are unaffected by culture or context. The relational, practical, and moral aspects of care are all critical for the nurses' role performance. However, culture, place, time, and personal attitude and knowledge all contribute to unequal opportunities for palliative care practice. The availability of nurses and their overall health expertise govern their position in palliative care. Acting as a coordinator and liaison between patient and family, other health professions, and different healthcare services is a prominent, but not always valued, role for nurses.

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