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Research Article

What is Person-Centred Care? A Qualitative Inquiry into Oncology Staff and Patient and Family Experience of Person-Centred Care

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ABSTRACT

Introduction: To investigate the understanding and practice of person-centred care by health care professionals and support staff at a cancer centre and to learn how patients and family members understand and experience person-centred care.

Methods: The study was conducted in two phases. Phase 1 used large wall mounted posters and marking pens in public areas of the cancer centre to gather comments from staff, volunteers, students, patients, family members, and visitors to answer the question, "What does person-centred care mean to you?" Phase 2 used a six-question, open-ended, paper-based questionnaire for staff and patients. A manual coding technique was used to derive themes from both posters and questionnaires.

Results: We derived 97 themes from the posters and 134 themes from 44 returned questionnaires (survey response rate of 37%). When the themes were combined and reprioritized, we learned that person-centred care is: (1) care that is caring, compassionate, and empathetic; (2) person or patient is the centre of focus; (3) care is unique to the individual's needs; and (4) person or patient is a part of their care. Furthermore, all staff should provide person-centred care.

Conclusions: Our findings describe what our staff, patients, and family members believe person-centred care is, and how it should be delivered. Based on this research study, we recommend promoting additional dialogue and continuing education opportunities for health care professionals and other front-line staff who will assist them to complete the statement, "I demonstrate person-centred care by..." to their own satisfaction in the future.

RÉSUMÉ

Introduction : Étudier la compréhension et la pratique des soins centrés sur la personne par les professionnels de la santé et le

personnel de soutien dans un centre de traitement du cancer et apprendre comment les patients et les membres de leurs familles comprennent et ressentent les soins centrés sur la personne.

Méthodologie : L'étude a été réalisée en deux phases. Dans la phase 1, de grandes affiches ont été installées sur les murs, avec des marqueurs, dans les aires communes du centre afin de recueillir les commentaires des employés, des bénévoles, des étudiants, des patients, des membres des familles et des visiteurs et leurs réponses à la question: « Que signifient les soins centrés sur la personne pour vous? ». L'étape 2 a utilisé un questionnaire papier de six questions ouvertes pour les employés et les patients. Une technique de codage manuel a été utilisée afin de recenser les thèmes des affiches et des questionnaires.

Résultats : Nous avons recensé 97 thèmes sur les affiches et 134 dans les 44 questionnaires retournés (taux de réponse de 37%). Après regroupement des thèmes et rétablissement des priorités, nous avons conclu que les soins centrés sur la personne sont définis comme suit: 1) des soins marqués par la sollicitude, la compassion et l'empathie; 2) la personne/le patient est le centre d'intérêt; 3) des soins adaptés aux besoins de la personne, et 4) la personne/le patient fait partie des soins. De plus, l'ensemble du personnel doit participer aux soins centrés sur la personne.

Conclusion : Nos constats décrivent ce que les employés, les patients et les membres de leurs familles dans notre centre croient que sont les soins centrés sur la personne, et comment ils devraient être rendus. Sur la base de cette recherche, nous recommandons de favoriser une augmentation du dialogue et des occasions de perfectionnement professionnel pour les professionnels de la santé et les autres membres du personnel de première ligne afin de les aider à terminer la phrase: « J'offre des soins centrés sur la personne par... » à leur propre satisfaction à l'avenir.

Conflicts of Interest: There are no conflicts of interest.

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Introduction

Many health care institutions are adopting or have adopted the philosophy of patient-centred or person-centred care to improve the safety and quality of care that they provide [1]. Generally speaking, patient-centred care refers to the process of engaging patients in decisions regarding how their own care is provided. When patients are invited to actively participate in their own care, there is greater agreement “on treatment plans, better health outcomes, and increased patient satisfaction” [2]. Although our institution has adopted this philosophy and definitions abound in the literature, through workplace conversations we learned that some of our colleagues had difficulty explaining person-centred care or used patient-centred and person-centred interchangeably. Furthermore, many people were not able to complete the statement, “I demonstrate patient or person-centred care by...” to their own satisfaction. For these reasons, we began to ask, “What is patient or person-centred care?” Do these terms refer to the same kind of care? If we are not able to describe patient or person-centred care, are we able to provide it?

We began with respected institutions such as the Institute of Medicine, Cancer Care Ontario, and The World Health Organization to clarify our understanding of the terms “patient” and “person-centred care”. The Institute of Medicine (IOM) [1] defines patient-centred care as: “Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions”. This definition emphasizes the importance of respect and meeting the needs and values of the patient, as well as the patient’s role in making decisions about their own care.

Cancer Care Ontario (CCO) [3] describes person-centred care (PCC) as an approach to “providing care that involves partnering with patients and health care providers to give patients a voice in the design and delivery of the care that they receive and to enable patients to be more active in their journey”. This definition emphasizes partnership and the importance of the individual being viewed as a person first (a whole being) before being viewed as a patient (an assigned role). Furthermore, CCO states that a focus on person-centred care will help to improve the patient experience and to provide better health outcomes and greater value by using resources wisely.

The World Health Organization (WHO) [4] describes person-centred care as “care approaches and practices that see the person as a whole with many levels of needs and goals, with these needs coming from their own personal social determinants of health”. The WHO also introduces the concept of “people-centred care: an approach to care that consciously

adopts individuals’, carers’, families’, and communities’ perspectives as participants in, and beneficiaries of, trusted health systems that respond to their needs and preferences in humane and holistic ways”. In order for care to be “people-centred,” individuals must have the “education and support they need to make decisions and participate in their own care”. People-centred care is “organized around the health needs and expectations of individuals, rather than diseases”.

From this first exploration of the literature, we see that the concept of patient, person, and people-centred care is multifaceted; patient, person, and people-centred care respects preferences, needs, values and goals, encourages action, and the patient’s voice. It features a humane, partnering and holistic nature, involving individuals, families, carers, communities, and health care professionals.

A sampling of the gerontology, nursing, and oncology literature also identified similar attributes of patient-centred and person-centred care. These authors stress the importance of patient participation and involvement; the relationship and communication between patient and clinician [5]; seeing the patient as a “whole” person within his or her psychological and social context, respecting patient values, preferences, and expressed needs [6, 7]; shared information and education; access to care; emotional support; involving family and friends; the continuity and coordination of care [8]; and care that involves an interdisciplinary team and provides support during treatment and at transitions [9].

Starfield [10] differentiates between patient-centred care and “person-focused care.” She argues that patient-centred care is episodic-oriented, while person-focused care refers to interrelationships with health care professionals over time, and is thus more holistic. Furthermore, she states that “care is better when it recognizes what patients’ problems are, rather than what the diagnosis is”. Dowse [11] expands this holistic view by describing the importance of “acknowledging the patient’s illness experiences and how they influence everyday life”. The ill person experiences the impact of more than just his or her disease. The Health Innovation Network [12] emphasizes the partnerships and relationships that we form with people; noting the philosophy “it is about doing things ‘with’ people rather than ‘to’ them”, as important to improve the quality of care. Coulter and Oldham [13] state that the patient perspective is the centre of person-centred care and requires “excellent listening, communication and...the capacity to respond flexibly to people’s individual needs”. Berwick [14] describes person-centred care as “the experience...of transparency, individualism, recognition, respect, dignity, and choice in all health matters, without exception, related to one’s person, circumstances, and relationships in health care”.

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