

Research Project

[Student no.]



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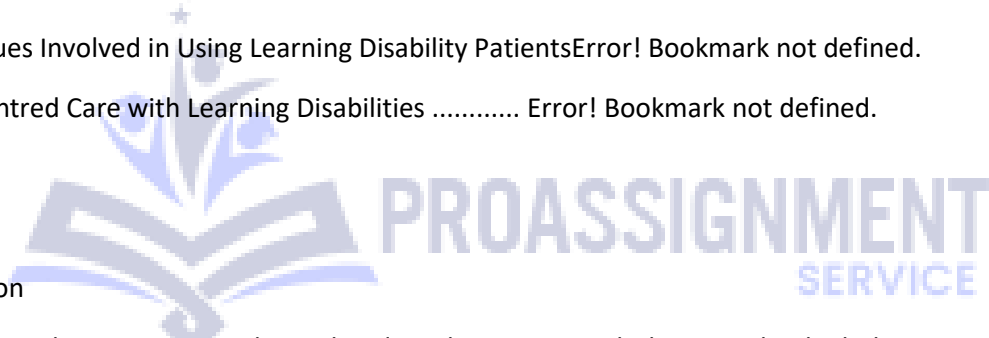
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## Introduction

Person-centred care is commonly used to describe an approach that is said to be holistic, prioritises the interests and needs of the individual of the system or its professionals, involves people in their care as fully as possible, and contribute in supporting people in making decisions and being in control as much as possible. In senior social care, 'personalisation' has evolved over the previous two decades to be recognised as an official mainstream practice, partially as a result of service users' campaigning (McCormack and McCance, 2016). During the same time period, advocates in healthcare initially emphasised 'patient-centred care.' For a variety of reasons, this has evolved into 'person-centred care' within the last six years: an acknowledgement that staff are individuals, too, and therefore need to be equally engaged in more individualised approaches; the word 'patient' represents the interdependence that personalisation aims to eliminate; and in a context of rising incorporation, 'patient' is the wrong word that describes users of certain services, including social care (Santana et al., 2018).

It is not only about delivering remarkable treatment professionally when it derives from the experience of the patient; it is also about patient treating with 'compassion and kindness, as well as improving patient and staff care by promoting person-centeredness in practice has the prospective of making a significant difference. While there is rising evidence that emancipatory practise development efforts may foster person-centred cultures, knowing how personcenteredness is effectively operationalised in practice is still a work in progress (Newman et al., 2019).

## Aims

This research project was aimed to build an understanding of the person-centred approach for learning disabilities and what it means in an acute setting.

## Objectives

1. To understand ethical issues involved in using learning disability patients in primary research.
2. To evaluate the influence of factors that facilitate person-centred care?
3. To demonstrate the understanding of nurses who delivers person centred care to individuals with learning disabilities?
4. To examine the barriers that come across delivering effective person-centred care?

## Ethics

The protection of human research through the application of appropriate ethical principles is of the utmost importance for all research. In high-quality research, ethical considerations may be crucial due to the deeper layers of the research process. This research project did not use any content without referring to the sites. It used all the authentic articles references. According to a statement published by the British Society of Sociologists on ethical practices, researchers should inform participants about the use of the data and allow them to use the material in the future. However, (Barrow et al., 2021) also pointed out that the approval was not a one-off event but would have to be renegotiated over time. There do not appear to be any guidelines for certain situations that require further approval (Barrow et al., 2021).

## Methodology

### Research Design

To achieve the objectives of this research project, the qualitative research design is used as it aids in the construction of background knowledge that is acquired by both the reader and the researcher in order to design a constructive project (Snyder, 2019).

### Search Method

The literature was found by searching electronic databases that were chosen to represent a comprehensive healthcare field, with no restrictions on publishing dates other than those covered by the databases. In Dec 2021, searches were conducted, and in Jan 2022, they were updated. To guarantee rigour in the search process, a specialised librarian was contacted while devising the search strategy. The literature was additionally gathered by hand searching references in the papers chosen from the electronic search using a snowballing method (Kumar, 2018).

### Selection of Literature

A total of 2038 documents were found through electronic database searches and reference list searches. The relevance of the articles was determined first by screening the title and abstract and then by

evaluating the full-text articles using a form designed to represent the study's eligibility criteria and objectives. This leaves a total of 23 studies for this review to consider. Two more articles from a previously included study were additionally collected because they offered new information and conclusions that seem to be relevant to the review's goal (Flick, 2015).

#### Data Analysis

The data analysis by qualitative research approach has been employed in this study since it is a way of systematically analysing communication (Flick, 2015). The analysis is a method of interpretation that focuses on the similarities and contrasts between various portions of the text and leads to the classification of the information into groups or themes. Qualitative content analysis is a procedure that swings back and forth between multiple levels of data rather than being a linear one. This is an analytical procedure in which early results such as codes, categories, or topics are compared and discussed to arrive at interpretive agreements (Pandey and Pandey, 2021).

The findings were first classified and condensed according to preferences for features of palliative care (data comparison). The preferences were then categorised into patterns and themes, with frequent comparisons and contrasts made between and within groupings of preferences, revealing both similarities and discrepancies. Finally, themes and subthemes were found, as well as their internal linkages, and their interconnections were discussed (Kumar, 2018).

#### Validity and Reliability

Validity and dependability were obtained by performing and documenting all of the processes outlined in the methods above in a rigorous and transparent manner, guided by wellknown and fundamental concepts (Snyder, 2019).

#### Literature Review

##### Person-Centred Care:

Patient-Centred Care that is also called PCC, as stated by Newman et al. (2019), is the care that is sensitive to and respectful of individual choices of the patient, their values and needs, as well as making sure that the values of the patient lead all decisions of healthcare. This concept highlights the necessity of treating patients with respect and addressing their needs and values, as well as the patient's responsibility in making decisions about their own health care. Person-centred care PCC is defined by (Sharma et al., 2015) as a method of providing care that entails collaborating with patients and healthtreatment professionals to offer patients a say in the design and delivery of their care and to enable them to be more active in their experience (Arakelian et al., 2017). This concept stresses collaboration and the value of treating each person as a full person before treating them as a patient (an assigned role). Moreover, according to CCO, a focus on person-centred care will assist in improving the patient experience, as well as produce better health outcomes and higher value by judiciously allocating resources. Person-centred care is defined by the World Health Organization (WHO) as methods and practises of care that considers the person as a whole, with various aspirations and needs levels and, with either of the needs arising out of their own particular socioeconomic health determinants (Byrne et al., 2020). The WHO also presents the idea of people-centred care, which is a method of care that

deliberately incorporates the caregivers, communities, families and individuals' perspectives as participants in reliable systems of health care's beneficiaries that give response to their preferences and needs in a holistic and humane manner. People should have the assistance and advice they need to make choices and engage in their own care in order for care to be people-centred. Individuals' health requirements and aspirations are prioritised over illnesses in people-centred care (Byrne et al., 2020).

### Ethical Issues Involved in Using Learning Disability Patients

A percentage of people in any group will have a learning impairment. This number exceeds 2% in the United Kingdom (UK) (Atkinson, 2018). People with learning impairments are more prone to experience social inequities, and people with learning disabilities are more exposed to violations of their rights being humans. Individuals with learning disabilities (also called PWLD) are therefore regarded to be at risk or may be vulnerable in particular situations as necessary assistance is lacking, or their requirements are not completely implicit. As a result, further procedures may be required to guarantee that they are treated fairly. Learning disabled people deserve to be treated "with the same respect and dignity as any other concerned citizen (Keywood, 2018).

The involvement of PWLD in the research of healthcare has presented practical and ethical difficulties. Experimentation on people with disabilities by a number of healthcare institutions and settings are examples of facing such difficulties. Attempts to avoid abuse and apparent barriers to getting permission, on the other hand, may result in PWLD not being included in the study. Concerns about the ability to consent for engaging in research, difficulties arising from the institutional care use that can influence the experience of a person in making decisions, and also PWLD's propensity to acquiesce to others' wishes and the inequality of power relationship between participant and researcher, both of which can make them more vulnerable to oppression, have been raised (Keywood, 2018). Considered that, for preventing from risking their potential injury and exploitation, ethics committees have been grown more restrictive in the approach for providing clearance for research with PWLD. However, it is probable that by using this method, they're discriminating against those with disabilities. It has been advised that researchers concentrate on including people with learning difficulties in their studies. In fact, removing PWLD from the study may deprive individuals of their ability to choose whether or not to participate and have their voices heard, as well as lead to insufficient research findings (Atkinson, 2018). People with learning impairments desire to participate in research, and with the right support and training, would do so while also reaping the benefits that research can provide, such as enhanced intellectual stimulation and self-esteem.

The informed permission of participants is a crucial component of the majority of research investigations involving human beings. Suitable information disclosure, freedom from compulsion, and ability (or competency) to assent are all necessary for informed consent (Sheehan et al., 2016). The legal requirements for capacity demand that an individual be able to comprehend related information, escalate the situational consequences, operate rational information, as well as interconnect their choice; while laws vary by country, the principles of comprehension, appreciation, reasoning and choice remain constant (Sharif, 2021).

The Mental Capacity Act, which requires researchers to presume capacity unless otherwise shown, applies to research in England and Wales. This might entail presenting information in a way that is specific to the person's communication needs. Potential participants should be given assistance in making their decision to participate or not. With proper contact with their care specialists, the

researcher must determine if a participant is potential and has the capability to grant their own permission to participate in the study. Researchers must meet specific requirements when recruiting volunteers who are not able-bodied (Keywood, 2018).

According to Brown et al. (2015), specialist learning disability teams are reduced to a bare minimum, with their job shifting to health facilitation (allowing clients to access generic services) and education via assistance for other health professionals in acute and primary care. Only when consent is provided without excessive pressure or coercion can it be deemed voluntary. The ability to provide or deny permission is referred to as competency. The notion that every adult (even an adult with a learning disability) possesses such capability is presumptive in English law, although it can be challenged and disputed. Patients have the right to receive accurate information in a way that allows them to comprehend the proposed investigation or treatment, as well as the alternatives and dangers involved (Brown et al., 2015).

#### Factors That Facilitate Person-Centred Care

At the organisational level, (Moore et al., 2017) identified seven major characteristics that lead to PCC. Leadership, patient and intimates' involvement at various levels, communication of the strategic PCC of organisation vision to the individuals of the organisation, making a safe and healthy workplace for caregivers, supportive technology, systematic feedback and measurement, and the built environment's quality were among the factors (Moore et al., 2017).

PCC values leadership. It guides organisations by building and maintaining their culture, providing services, and guaranteeing proper governance. In regards to paving the way, giving direction, and resources for PCC, empirical research highlights leadership commitment and support. The amount to which healthcare organisations arrange a match between PCC objectives, vision, coherent strategy as well as everyday operational actions of health institutions is determined by the level of strong leadership to PCC. For example, stating the organisation's patient-centred mission during employee onboarding has been proven to encourage PCC (Santana et al., 2018).

One of PCC's basic facilitators is suitable sharing of power between patients and health care providers, which is linked to patient and family engagement in care decision-making. At many levels of the organisation, patients and families may be included in the decision-making of healthcare (Santana et al., 2018). The establishment of a patient advisory board as well as involving them in decisions of the organisation such as recruitment interviews, activities for quality improvement and service design have been mentioned in studies as ways for healthcare organisations to involve patients as well as their families in healthcare decision-making. Furthermore, providing pleasant work environments and caring for providers are important organisational-level elements that encourage PCC. Social support, appropriate working circumstances, job features, employee training and development, and communication are all aspects of the workplace environment. This is an important part of employee motivation, and they have an impact on professionals of healthcare performance and the quality of treatment provided to patients (O'connor et al., 2016).

The collection of patient measurements and the feedback of performance related to PCC are critical components of healthcare quality improvement. Patient feedback might involve mystery shopping, direct observation, questionnaires, and the use of databases to form patient complaints about gathering information about a patient's treatment experience. Healthcare organisations should invest in

technology like health information technology systems to facilitate systematic continuity and measurement of care (Cancelliere et al., 2016). Patient-focused information systems, for example, have been proposed as a way to improve the accessibility to patient data, stimulate patient engagement in healthcare, and save office space. As a result, it is envisaged that healthcare executives would spend in health IT for supporting PCC. The atmosphere in which care is administered, according to (Santana et al., 2018), is extremely important to PCC. The process of healing and the patient experience of care is considered to be inextricably tied to the physical setting in which treatment is administered. Patients' assessments of the quality of treatment, for example, are mostly reliant on physical signals such as the cleanliness and silence of the physical space and environment physical, the health facility, according to research (Moore et al., 2017). As a result, the built environment plays a vital role in PCC. As a result, the aforementioned organisational-level elements might be considered PCC's 'catalytic agents'.

#### Nurses Understanding of Delivering Person-Centred Care with Learning Disabilities

Learning disability nurses are associated with an instinctive approach and a defined set of principles like inclusiveness and person-centeredness – with evidence-based treatment and outcomes-focused to enhance the lives of persons with learning disabilities (Keywood, 2018).

Nursing for adults with learning disabilities entails assisting people with a wide range of requirements. Assessment, communication, health promotion, education, and empowerment are all skills that are required. Nurses' capacity to create relationships and interact with patients has a greater impact on patient outcomes than their technical abilities. This can make the position more difficult to define and quantify than in nursing professions, where the goal is to help sick patients get better (Atkinson, 2018).

Learning disability nursing has a lesser prestige than all the other nursing specialities, and its purpose is frequently questioned. This is partially a holdover from the period when learning disability nurses were locked up in long-term facilities and accused of suffering from a "parallel stigma" to the patients. Learning disability nurses, on the other hand, have struggled to articulate their distinctive contributions and build a solid evidence foundation in comparison to colleagues from other nursing disciplines (Sheehan et al., 2016).

#### Barriers to Deliver Effective Person-Centred Care

These components were found in health facilities that are served as barriers to PCC, according to research. PCC leadership conception, a lack of objectives and adequate activity for PCC, communication issues, ownership type, degree of centralisation, and budgetary limits were among them.

According to Cancelliere et al. (2016), lack of PCC's visionary leadership is also a barrier as PCC was viewed in a variety of ways by researchers. Some researchers defined PCC as everything that goes into providing care for patients, including logistics, infrastructure, pay, and training. Others described PCC as developing a nurse care plan for patients individually, while others defined it as customer care, which they defined as paying attention to people and their requirements while delivering quality care. Patientcentred care was also defined as taking steps to foster positive staff attitudes and respect for patients, as well as keeping the hospital clean and guaranteeing adequate people and resources for care delivery (O'connor et al., 2016).

The lack of goals and sufficient activities for PCC can also create difficulty as in the hospitals, no defined PCC strategic goals, targets, or guidelines to reflect the precise change hospital management plan to

report on PCC are discovered by researchers. Furthermore, the job descriptions of the various professional groups did not appear to include any explicit tasks for PCC personnel. The purpose and value statements, as well as the hospitals' patient-focus policies, are determined to be incompatible. While PCC is included in the purpose and value statements, the patient-centred policy in effect was customer service (Moore et al., 2017).

Language barriers, fear of victimisation, and patients' and families' hesitation in reporting unfair treatment, raising questions or seeking clarifications were cited by researchers as roadblocks to patient education and initiatives to engage patients in care choices. The patient-provider relationship, particularly the nurse-patient connection, was claimed to be harmed as a result of this circumstance (Cancelliere et al., 2016). One of the researchers stated that nurse-patient misunderstandings at her hospital were more of a "pseudo-conflict" coming from seeming differences between nurses and patients, which frequently resulted in nurse stereotyping. One of the reasons for miscommunication between carers and patients was caregivers' demand for unlawful payments (Santana et al., 2018).

According to (O'connor et al., 2016), the ownership style is also among the barriers of person-centred care as in the hospitals, no defined PCC strategic goals, targets, or guidelines to reflect the precise change hospital management plan to report on PCC are discovered according to (Edvardsson, 2015). Furthermore, the job descriptions of the various professional groups do not appear to include any explicit tasks for PCC personnel. The purpose and value statements, as well as the hospitals' patientfocus policies, are determined to be incompatible. While PCC is included in the purpose and value statements, the patient-centred policy in effect was customer service. Participants noted that the ownership position of hospitals influences the policies and procedures used in hospital management, which has significant consequences for PCC (Santana et al., 2018).

## Results and Findings

Leadership commitment to PCC was demonstrated by the values of patient-centred and its mission statements. Such organisational statements can convey to hospital personnel that the hospitals are face-lifting patient-centred care and also that person-centred care is the fundamental principle that drives the delivery of care in the institutions, and they can help them achieve their vision. The findings suggest that hospital executives are interested in reacting to patient assessment and addressing bedside concerns in management review meetings (Arakelian et al., 2017). This shows management's commitment to PCC and is consistent with the literature of healthcare facilities with a track record for enhancing patient experience committed quality time to discuss patient experience concerns at meetings. This research project also found support from top management for PCC in terms of financing for staff training, the availability of needed resources, community participation, and patient follow-up, all of which are critical in building the environment for accessible and responsive care. This study's findings on management support for PCC corroborate those found in the United Kingdom.

In conclusion, PCC was hampered by a strong and well-developed biomedical approach, as well as established professional attitudes that were difficult to shift. The intervention's design, demographic, care environment, and established documentation systems all presented challenges, according to the investigators.

This research project would advocate broadening the inclusion criterion for granting a larger variety of individuals with learning disabilities to participate in research if it would be judged low risk and has the



capability to help the community with the patient with learning disabilities. Because of general advances in healthcare, the number of persons who lack capacity owing to intellectual impairments or diseases such as dementia is on the rise. They should not, however, be barred from engaging in research in order to guarantee that their needs are satisfied, as they are frequently the group most in need of health and social care. Consideration of study participation as a human rights problem is one method to ensure that the dignity and needs of PWLD are not disregarded. It is envisaged that a softer approach to Patients with learning disabilities recruiting would result in a larger body of information about their health and wellbeing (Arakelian et al., 2017).

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