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The presence of a patient's voice in the care process: Implications for patient-centeredness and shared decision making

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Research use and Impact Assessment

Introduction: the value of patient-centred care

- A patient centred approach to care is increasingly recognised as the hallmark of adequate healthcare delivery. This kind of care
 - emphasises the visibility of a patient’s voice
 - holistic approach to care
 - most essential where there is a need to address psychosocial factors relevant to a patient’s problem(Rohrer, Wilshusen, Adamson and Merry 2008: 548)

Introduction contd

Also essential in cases where :

- chronic care since treatment success depends on highly on patient buy-in
- Though there is no agreed upon definition, there is general consensus about:
 - its value in facilitating shared decision making about treatment and care
 - the centrality of the patients' voice and agency (1) in

patient centred care

Social science that makes a difference

¹ The rejection of a passive positionality of patients and an assumption of an active one (Bishop and Yardley (2004)

Problem

- Despite general consensus on the value of patient-centredness and of the visibility of a patient's voice, there is paucity of literature that
 - traces the presence of the patient's voice in health care centres where
 - the organisation of the care process is multifaceted
 - and services are provided by linguistically diverse healthcare teams
 - ❖ without such studies it becomes to know whether patient's are factored in the care process and if not, how can the situation be redressed



Aim

- This paper explores the presence of the patient's voice in the care process in two HIV and AIDS care centres in Lesotho, with the goal of establishing the extent to which the two clinics provide patient-centred care

Theoretical Framework

- **Theoretical framework**-Mead and Bowers (2000) dimensions of patient centred care, and Blackman and Sadler-Smith (2009) who provide a framework explaining the concept of voice.
- The frameworks helps to conceptualise patient-centred care and its components and the relevant of the patients' voice in patient-centeredness.

Dimensions of Patient-Centred Care

- Mead and Bower describes patient centredness in terms of 5 dimensions (2000: 1088-1090) dimensions of patient-centeredness :
 - Biopsychosocial dimension which takes a broader account of a persons' illness
 - Patient as a person wherein a patient is taken as an experiencing individual with own interpretation of their illness

Mead and Bower Cont

- an egalitarian doctor-patient relationship in which power and responsibility are shared;
- a good doctor-patient relationship;
- doctor as a person with personal qualities that have an influence on medical decisions taken;
- ❖ the above stated dimensions reflect the necessity for a patient's voice, and of successful patient-centred communication in the achievement of this kind of care.

Voice

- Voice (Blackman and Sadler-Smith, 2009: 573-578) -an expression or manifestation of different forms of knowledge that a speaker has.
- A voice can be suppressed or silenced by several factors such as:
 - The influence of power relations
 - Language barrier between participants,
 - A feeling that the participant is less knowledgeable in the subject being discussed.

Methods

- The data was collected from two clinics that offer HIV care in Lesotho.
- The two clinics are staffed by expatriate doctors who are:
 - mostly from Francophone countries such as Congo, Cameroon and Gabon
 - mostly first language speakers of African languages such as Kiswahili, Lingala, Tshiluba, Ewondo and second language speakers of French.

Findings

- Care is organised in three phases
 - Pre-consultation
 - Consultation
 - Post consultation
 - In all phases the patient's voice is silenced either through Repression or Suppression

Repression and suppression defined

- Repression- a controlled exclusion of certain pieces of information in Blackman and Sadler-Smith (2009: 577),
- Suppression -involuntary silence in perceived compliance with the norms of the interactional event in Blackman and Sadler-Smith (2009: 577)

Pre-consultation

- Initial phase -an attempt is made to know and understand the patient's problem
- the patient's experiential knowledge as an individual who experiences the problem is very crucial
- Presence of patient's voice is ideal
- However, silencing of this voice through suppression was common

Repression of patients voice

Repression Type	Examples	Point of Occurrence
Topic pre-announcement	“I tell them in advance that here we stick to the HIV problem only” (<i>nurse</i>)	History taking
	“In the morning we brief them and tell them to talk only about their HIV related problem to save time” (<i>receptionist</i>)	Reception
Asking guiding questions	“We ask questions to guide them” (<i>nurse</i>) “They ask questions that they like” (<i>patient</i>)	History-taking room
Guiding information flow	“We stop them when they go overboard...” (<i>nurse</i>) “They tell you no, don’t talk about that” (<i>patient</i>)	History-taking room

The Consultation

- In the physicians' consultation the main purpose of communication is
 - to fully understand the problem
 - arrive at a recommend treatment option for the patient.
- Communication is characterised by detailed accounts of the health complaint by the patient and interpretation of that account and of test results
- Shared understanding of the problem and shared decision-making on treatment is central (Moore, 2008; Rohrer et al., 2008).

Suppression of the patients voice

- Presence of Interpreter- Interpreter does most of the talking
- Language Barrier
- Patients perception of being non experts

Conclusion

- The organisation of the care process into different service points provides a good environment for the achievement of patient-centeredness
- However, it also requires
 - healthcare provider who is skilful in patient centred communication
 - a patient whose voice is present throughout the process

Conclusion Cont

- Despite the value attached to a patient's voice, it gets silenced in all phases by
 - suppression,
 - repression and
 - also withholding of information by patients themselves.

Recommendations

- healthcare system makes provision for human resources training in patient centred communication among nurses and interpreters
- The language barrier between patients and doctors should also be attended to in order to facilitate patient empowerment to voice their problems directly to doctors during the consultation.
- The improved communication will result in the presence of the patient's voice in the consultation and therefore increase patient's agency and ownership of the care process.