Learner-Centred and Culturally Responsive Patient Education:

Drawing on traditions of cultural development and popular education

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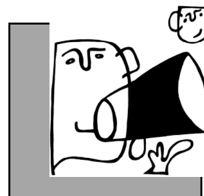

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Executive Summary

This discussion paper describes and discusses the possibilities of learner-centred patient education practice. In particular, the authors reviewed literature that constructs culture as an asset rather than as a barrier in patient education. Drawing on traditions of community cultural development and popular education, the authors discuss the possibilities of using the cultural experiences of patients and health care practitioners to inform patient education materials and practices. Cultural experience directly shapes what and how people learn. Therefore, good education practice should engage with it. To help patient-educators engage with cultural experiences they need highly developed questioning and listening skills. Important aids for the questioning and listening processes are accounts of cultural experiences.

Due to a shift from curing to caring for an increasingly older and diverse patient population, there is an increasingly strong voice within the health community advocating for patient-centred care, active participation of patients in their treatment, capacity building and creative and appropriate patient education approaches that are meaningful, relevant and effective. Patient education is a vital aspect of health care practice because effective patient learning ensures safe and effective discharge, competent patient self-management in the community and prevention of unnecessary readmissions to the hospital. In a busy hospital with short length of stay for patients, the need for patients to be informed about their disease processes and health behaviour change required from patients is a challenging task. A patient-centred approach takes a fresh look at these issues and challenges. It values patients' perspectives, experiences and beliefs. It embraces not only physical needs but also social and diverse needs. Patient-centred care advocates for collaborative clinical decision-making and realistic approaches to professional practice (Higgs & Titchen 2001, Trede & Higgs 2003).

Further today's hospitals' key challenge is to meaningfully engage with and encourage participation of diverse communities to foster their identification with the hospital and a sense of ownership of their treatment and place of treatment. Most hospitals have guidelines for best practice or education programs for the delivery of healthcare services to patients from culturally diverse backgrounds. Most though are designed for specific groups with an emphasis on providing access to translated materials and resources and to "cultural brokers" or interpreters who perform a liaison function between health professional and patient (Multicultural Access Unit 2000; 2001; and Diversity Rx nd). The provision of these services does not guarantee the provision of patient-centred healthcare. Diversity includes ethnic background, class, gender, socio-economic status, regional differences, religious beliefs, sexual orientation and age, amongst others. Diversity health acknowledges commonalities among cultures in relation to care. However, diversity also acknowledges difference amongst cultural groups and points towards individual perspectives. As Allotey, Manderson and Reidpath's (2002) study (conducted in Queensland to research and develop cultural resource materials accessible and useable in clinical and community settings with patients of non-Anglo-Celtic backgrounds) suggests best practice is not to follow simple ready-made rules but rather for patients to negotiate with clinicians and clinicians to encourage patients' participation.

There is a lack of alternative approaches adopted to patient education, other than the didactic, traditional teaching approach supplemented with flipcharts, posters or brochures. Staff at POWH are aware of the shortcomings of a didactic approach to patient education and they would welcome piloting alternative approaches.

To address these shifts and challenges, there is a need to develop strategies to facilitate transformation of patient education towards a more patient-centred approach. The authors of this paper argue that community cultural development (CCD) practices have a lot to offer. CCD is not a practice which is traditionally associated with the practice of arts for health work in hospitals. That tradition has largely been located in either art therapy (the use of creativity to treat a pathology or labelled condition with a clinical aim) or placemaking (practices which create a place or improves the aesthetics of a place through the use of design, architecture, landscaping, occupational therapy, cultural planning and public arts to distract by creating a soothing environment). The field of practice we are concerned with here, though, is the use of CCD in a healthcare setting; a participatory approach to health and wellbeing focused on working with the whole person to help them create and transform a space outside of the illness focused world they inhabit. CCD provides a potential for all stakeholders of patient education to facilitate effective and culturally competent patient learning. Through participation in the arts patients are empowered to take control in the decision making process of their wellbeing or treatment. In this context art is seen as a powerful tool to build and consult communities and give voice to socially excluded groups (Meyrick 2001). Through participation in the arts clinicians can be trained to promote empathy and communication with their patients (Meyrick 2001). The key principles that underpin CCD and as well as patient-centred patient education are participation, collaboration and a learner-centred approach. All these principles will enhance the learning experience in relation to health.

The authors therefore recommend that a professional writer experienced in CCD should be employed by POWH’s diversity health department to engage with patients and clinicians in a creative practice to address patient education. This project would build and extend on the knowledge and experiences of the participants focusing on issues and problems that are particular to the two respective groups. Value should be placed on the patients as well as on the clinicians’ knowledge and perspectives as experts. This would lay the groundwork for building a whole-of-community approach to analysing and acting on chosen health education and care issues where CCD processes would be used as a medium for both clinicians and patients to express their diversity and make their health beliefs, priorities and professional or personal perceptions about disease explicit in a safe and non-judgmental environment. The engagement would emphasise participation, learner-focus and collaboration. The products will be used as educational material for clinicians and patients as well as a quality art product that can be displayed in the ward.

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Introduction

Imagine working with a group of homeless young people, a group of middle aged women from a housing estate, or a group of elderly Greek men with a heart condition. What strategy would help achieve, in the long term, a rhetoric of empowerment for these people to take control of their lives, build communities or develop and share an understanding of their medical condition to look after their health? Counselling, anger management, occupational therapy, seminar, translated or plain English printed material, etc.?

Now, imagine these people collaborating on a film (researching, scripting, editing, casting…), collaborating on a co-authored book or collaborating on a painting. What sort of value might that have for them especially if the film is then screened on SBS, the book published and sold at conferences and forums, or the painting purchased and exhibited in the hospital?

In this practice, called community cultural development (CCD), artists have a key role in this collaboration. These practitioners argue that they can engage with a group of marginalised people more quickly and more significantly than through the didactic and more commonly used strategies such as counselling, seminars, printed material, etc. because they don't engage people within a deficit framework and work through the barriers to education such as past fears associated with negative learning experiences, top-down approaches and auto-censorship. The role of the artist is to support a group of people create something and express themselves which leads to empowerment through an increased sense of self-efficacy and improved communication.

This is of course but one of a variety of methods which can be used to improve patient-centred care and education, but has a lot to offer the healthcare community's search for innovative approaches to healthcare practice.

Due to a shift from curing to caring for an increasingly older and diverse patient population and a growing consumer voice (Higgs & Titchen 2001). The aim of this document is to help Prince of Wales Hospital's (POWH) Diversity Health Department develop strategies that answer that need. POWH's key challenge is to meaningfully engage with and encourage participation of diverse communities to foster their identification with the hospital and a sense of ownership of their treatment and place of treatment. In the following, we argue that to address this challenge there is a need for a patient education practice that is underpinned by patient-centred care, diversity health, CCD, and popular education frameworks.

There is an increasingly strong voice within the health community advocating for patient-centred care (Fulford et al 1996), active participation of patients in their treatment (Cox 1999, Skelton 1998), capacity building (Hawe et al 1997) and creative and appropriate patient education approaches that are meaningful, relevant and effective for an increasingly diverse clientele (Flores 2000). Further, Baum et al in 1992 stated that there was a need for a rebalance of health to include social intervention rather than a sole reliance / focus on curing the sick in a purely clinical way (cited in Clifford 1997).

In 2002, POWH's Multicultural Health Unit undertook a survey (MHU 2002) that identified issues such as community concern about inappropriate and insensitive communication, dissatisfaction with type and method of information provision and a sense of lack of respect that questions the efficiency and effectiveness of current healthcare practices. An unpublished pilot study exploring current approaches to patient education in the cardiac wards at POWH revealed that

clinicians predominantly applied a knowledge dissemination approach. Such an approach focussed on risk factor modifications and life style changes from a biophysical perspective. It excluded emotional, family, social and cultural contexts and perceptions of health problems. Although the participants in this study recognised the limitations of this didactic approach to patient education no alternative approaches were suggested or adopted. All patients received the same approach to patient education regardless of their diverse background and needs.

Further, Bergin and Fairbrother (2000 and 2001) conducted a study on staff empowerment. Their findings were that nurses had the technical knowledge and knew the facts of cardiac patient education but they were not sufficiently learner-centred and lacked know-how. 30% of patients claimed that they had not received any patient education. Nurses appeared to have no systematic approach to patient education. They did not answer all the patients' questions and used too technical terms.

A follow-up study was conducted by Flowers and Trede with Bergin and Fairbrother to explore the learner-centred teaching skills of nurses and aims to produce guidelines for best practice in cardiac patient education. By learner-centred education they meant nurses being able to not simply identify what patients want to, and should learn, but being able to identify what helping and educational strategies will be most effective for particular patients. An assumption was being made that patients' learning needs are different, how patients best learn varies and therefore good education practice requires being able to employ different facilitation skills. Findings from this study revealed that clinicians are predominantly using therapist-centred, medical approaches to patient education. It confirmed that diversity health issues are not integrated well into patient education. There is a lack of alternative approaches adopted to patient education, other than the didactic, traditional teaching approach supplemented with flipcharts, posters or brochures. Staff at POWH are aware of the shortcomings of a didactic approach to patient education and they would welcome piloting alternative approaches.

There is very little knowledge relating to CCD at POWH and there is a dearth of literature that addresses CCD and patient education in hospital settings. The focus of the literature in CCD in this context has been predominantly in its therapeutic and placemaking capacities. These processes have particularly strong support in the United Kingdom. The Exeter Healthcare Arts Project for example, provides a useful evaluation of the arts processes. However, we seek to expand the scope of CCD to clinical practice and to apply it as a tool for culturally competent patient education practices.

In Australia several key sites are taking leading roles in integrating CCD approaches into program planning including:

Liverpool Hospital, NSW;

Westmead Children's Hospital, NSW;

North Richmond Community Health Centre, Victoria;

Mater Children's Hospital, Queensland;

Wesley Hospital, Queensland;

Cellblock Youth Health Service, NSW;

High Street Youth Health Service, NSW.

The Centre for Popular Education (The Centre) at the University of Technology, Sydney, a leader in the research and evaluation of CCD initiatives, was commissioned by the Diversity Health Department to write a discussion paper which would crystallise common values of CCD, patient-centred care, popular education and diversity health by addressing the following major questions:

1) How can diverse needs of patients be integrated in effective patient education practices?

2) What is the scope of CCD approaches to address the needs of increasingly diverse patients?

The primary field of practice that informs this discussion paper is the field of patient education. This is then complemented by a review of the forms and traditions of three broad fields of practice including diversity health, popular education and CCD. The final section of this paper makes recommendations on the potential implementation of a CCD pilot project at POWH.

Patient Education Reviewed

Contextualising Patient Education

Patient-clinician relationships have become more complex, quality care needs to be provided to a wider and more diverse range of the population by a wider and also diverse range of clinicians (Gardenswartz & Rowe 1998). On the one hand, due to the information revolution and consumer society of today, an educated patient is fast becoming a reality that clinicians are faced with but also a desirable situation to help clinicians provide a more efficient service and reduce the level of litigation and complaints. In this instance, patients want to discuss options with their doctors and take part in the choice of their treatment. On the other hand, though, the very advent of this consumerist society, information revolution and mass education has left behind the poor and socially excluded of which a high percentage were born overseas and belong to culturally diverse or marginalised groups and created barriers that prevent people from diverse backgrounds from participating in health at all levels (DHS nd). In this instance, the lack of education and access to resources means that they are less likely to question decisions or discuss options for treatments with their doctors (Neuberger 2000).

Moyers (1993) acknowledged that not all patients want to share decision-making powers and be in an empowering or even emancipatory relationship. Yet, educated patients are more likely to know how to care for themselves and their family and therefore prevent some illnesses as well as "make responsible use of health services and to get more benefit from any treatment they undergo" (Neuberger 2000, p.10). It is therefore in the advantage of the clinicians to work with and encourage the development of educated patients. The key question then concerning patient education evolves around how to educate patients to have a sense of choice and control (accept, reject or resist options/decision) and participate in his/her wellbeing as an informed individual? How can clinicians elicit patient perspectives?

An educated patient is, therefore, a patient who has greater access to information which gives them a greater awareness of options as well as increases their demand for more information and involvement in their own healthcare (Neuberger 2000; Stukin 2001 and Brinker, 2001). This means for clinicians that an educated patient is a patient who:

- has been adequately consulted
- has been listened to
- has been taken seriously
- is in a position to give informed consent
- is knowledgeable about relevant medical facts
- understands the perspectives and interests of clinicians
- has critically reflected upon her/his own values, culture and perspectives

This has repercussions on the patients-clinicians relationship. Late 20th century has seen a shift in the perception of the unfailing doctor and of absolute truth. It is now clear to patients that the Western medical system is as much a cultural product as the Chinese or the Arabic system. There are greater expectations

placed on doctors in a consumer approach to healthcare. Patients are expecting a more equal and humane relationship with their doctors (Neuberger 2000 and Brinker 2001). The relationship is likely to have characteristics of cross-cultural relationships and therefore require negotiation around protocols of engagement. It is the skill of a patient-centred clinician to establish the negotiation process and identify the potential roles each is able to play in the relationship. It would be the role of the clinician to know in what context within a hospital setting patient-centred approaches are most conducive to patient education.

There is substantive literature on clinician-patient relationships. The seminal paper by Szasz and Hollander (1956) explored the doctor-patient relationship from a philosophical perspective. It described the role of clinicians as 'doing something to patients', or telling patient what to do, or helping patients to help themselves. Three practice models are differentiated:

Active-passive (medical model-centred)

Guidance-cooperation (negotiated or participatory-centred)

Mutual participation (emancipatory-centred).

Emanuel and Emanuel (1992) described four models to clinician-patient relationships:

Paternalistic model (clinician tells patients what is best for them),

Informative model (clinician is expert and provides the choices that patient can choose from),

Interpretive model (clinician takes the role of counsellor and helps in the process of decision making),

Deliberative model (clinician provides information and encourages patients to explore their values and what decision would suit their situation best).

The use of the different models above all have a role to play at a particular point in time and have their justification. It is for the hospital staff to decide in collaboration with the patient in what context (medical and social) to apply what approach. Clinicians as well as patients may change their approaches according to individual situations. For instance, within the process of a disease a patient may want to be more passive in acute stages and more active and self-determining in chronic and longer-term stages.

So what does that mean when dealing with diversity care? Today, most hospitals have guidelines for best practice or education programs for the delivery of healthcare services to patients from culturally diverse backgrounds. Most though are designed for specific groups with an emphasis on providing access to translated materials and resources and to "cultural brokers" or interpreters who perform a liaison function between health professional and patient (Multicultural Access Unit 2000; 2001; and Diversity Rx nd). However, the provision of these services does not guarantee the provision of patient-centred healthcare. Rather, what is needed is an approach that sees cultural diversity or diversity as the differences that distinguish people with an understanding that diversity exists between but also within groups. In this sense, diversity includes ethnic background, class, gender, socio-economic status, regional differences, religious beliefs, sexual orientation and age, amongst others. Further, this practice may not only focus on differences but also on commonalities among cultures in

relation to care. As Allotey, Manderson and Reidpath's (2002) study conducted in Queensland to research and develop cultural resource materials accessible and useable in clinical and community settings with patients of non-Anglo-Celtic backgrounds suggests best practice is not to follow simple ready-made rules but rather for patients to negotiate with clinicians and clinicians to encourage patients' participation.

Providing an interpreting service is important but needs to be one component of a patient-centred model of care. Victoria's Department of Health Services recommends to "use a variety of community development approaches to involve patients from non-English speaking backgrounds in addressing [the gaps in the provision of culturally and linguistically appropriate information]." and to "develop innovative strategies to provide people from non-English speaking backgrounds with appropriate information" (DHS nd, p.53).

Forms & traditions of patient education

"Healthcare is a 'knowledge business'" (Smith 2002, p.1432) that need not be only reliant on didactic modes of education. According to Clifford (1997), the Western healthcare system can be divided into 2 distinct models:

> the bio-medical focusing on individuals' malfunction or illness and the treatment of the body in isolation from the mind of the mostly institutionalised healthcare environment; and
>
> the holistic model linking body, mind, socio-economic and cultural context of the mostly community healthcare environment (Part of the Whitlam Government's social experiment to provide access to health for all and the subsequent implementation of community health organisations).

Models of patient education practices can be well explained and understood by analysing the role of clinicians, the role of patients, the clinician-patient relationship, the nature of the health problem, expected health outcomes, the working definitions of health and illness and the definition of practice knowledge. This part of the discussion paper will describe facets of approaches to patient education within their philosophical paradigms. Philosophical paradigms disclose assumptions about what is knowledge and what can be known and how it can be known. By making assumptions and values that underpin approaches to patient-centred care transparent we hope to enhance understanding of patient-centred care approaches. Paradigms also provide conceptual underpinnings for principles and practices. First, a medical model-centred and then two facets of patient-centred approaches to patient education are described and their philosophical paradigm discussed. Table 1 summarises their differences.

A medical model-centred approach to patient education

Traditionally patient education has followed the medical model approach located within a positivist paradigm. Patient education was defined as 'a planned learning experience using a combination of methods such as teaching, counselling, and behaviour modification techniques which influence patients' knowledge and health behavior…" (Bartlett, 1985, p.667). Patient education is based on the assumption that health behaviour will change once patients receive correct and relevant medical information:

> knowledge change → attitude change → behaviour change.

Another assumption is that in this traditional patient education model authority and truth in regards to health matters are the expertise of the medical profession and other ways of knowing about health are discarded as myths.

In its extreme version, the medical model-centred approach describes health as the absence of disease within the natural world. Knowledge about health and illness is generated using empirico-analytical approaches (controlling variables, dissecting health problems into its parts, separating body from mind and spirit). Health is measured in quantitative terms. Evidence is based on sense data only; whatever cannot be seen, smelt, felt, tasted or heard is not accepted as evidence. This technical knowledge predominantly forms the basis for patient education. The medical model approach to patient education focuses on the biophysical and biomedical functions. The medical model-centred approach has been described as an active-passive model (Szasz and Hollender 1956), control approach (Skelton 1997) or therapist-centred approach (Trede 2000).

What are the intentions of medical model-centred clinicians? Their intentions are underpinned by the empirico-analytical or positivist paradigms. These paradigms define knowledge as objective, value-free, bias-free, valid, reliable, transferable and generalisable. The aim within these paradigms is to predict and control the natural world. In Western cultures such a model is perceived as best practice as it adheres to rationality, productivity, self-responsibility and individualism. Patient education and disease prevention is seen as promising freedom, control and health, something that is perceived as being naturally good. This medical-centred model is somewhat taken-for-granted by clinicians as well as by patients (Skelton 1997). Though having some benefits, the implications of this positivist paradigm for the healthcare community are:

Health is located in the physical world only

Practice knowledge is based on empirical data only

Only physical aspects of patients is of interest and concern

Clinician-patient relationships equal expert-lay relationships

Evidence has an outcome-driven, quantitative connotation

The implications for patient education are:

One-way information dissemination using traditional teaching and learning approaches (brochures, flip charts, posters, etc.)

Health experts tell ‘ignorant’ patients what is best for them from an authoritarian medical/health perspective

Medical knowledge represents the ‘truth’ (there is medical knowledge and lay beliefs)

Educational emphasis is on content and conveying instructions

Behaviour change is a linear process based on the assumption that once medical knowledge is understood, attitudes will change resulting in behaviour change (behaviourist model)

Interventions (for example lifestyle choices) are limited to what has been proven with evidence-based practice

Excludes other ways of knowing (emotions, values, personal history and subjectivity are excluded. Only the physical aspects of health are included in this approach to patient education)

Within the empirico-analytical paradigm technology prevails over humanity. Randomised controlled trials prevail over other research methodologies and didactic teaching prevails over other ways of teaching and learning. Such a philosophical stance to health gives clinicians authority, expert status and a license to know best what patients need in regard to health.

For medical model-centred clinicians biophysical facts and disease theory govern their approach to care and patient education. Such a model advocates closed questions evolving around the disease symptoms and possible complications of care, not leaving room for patients to bring their concerns into the conversation. The clinician is in control of the consultation and makes decisions for patients expecting improved biomedical outcomes.

Some critiques of the positivistic values and medical model-centred approaches to patient education include:

It is context stripping

It excludes meaning and purpose

Its statistical relevance has no meaning for individuals

Scientific method cannot postulate the 'real and only' truth

Theories, facts and statements are not value-free

There is no objective observation

A patient-centred approach to patient education

Patient-centred care is a term that can mean different approaches to care to different people. In fact all clinical care could be labelled patient-centred as all care is directed towards patients. A medical centre that offers state-of-the-art technology and efficient administrative services might be the ideal workplace for clinicians. Such a medical centre might not necessarily be the ideal place for patients as the technical aspect can be alienating and intimidating. The essence of patient-centred care is to include the patient in the work of clinicians (Fulford 1996). It has a connotation of 'doing with' rather than 'doing to' patients. A patient-centred care approach is concerned with understanding healthcare needs from a patient perspective. Taking patients seriously and integrating their health beliefs into healthcare consultations can a daunting exercise for clinicians. It has implications for who defines what the relevant issues are, how decisions are made and who is responsible for health.

"Patient centred care seeks to overcome two centuries of authoritarianism to empower the patient." (Miles 1997, p.270). A patient-centred approach emphasises empathy, understanding patients' perspectives, starting where they are at, being relevant to their immediate needs. This approach is driven by:

Patient complaint units

Lawsuits against doctors

- Patient-centred care movement
- Need for informed consent and its legal implications
- Health promotion movement (emphasis on well-being instead of absence of disease),
- Diversity health, multiculturalism (mutual respect, context driven)
- Dissatisfaction of clinicians with didactic approach
- Research demonstrating evidence of ineffectiveness of didactic approach
- Advent of non-curable disease (for example HIV/AIDS and cancer)
- Increase in chronic diseases where education is the only effective medical intervention

Patient-centred approaches to healthcare and patient education have developed as a response to increased patient dissatisfaction (Gordon and Edwards 1995). A patient-centred approach takes a fresh look at issues surrounding collaborative decision-making and realistic approaches to professional practice (Higgs & Titchen 2001). A patient-centred approach values patients' perspectives, experiences and beliefs. It embraces not only physical needs but also social and diverse other needs. A patient-centred approach aspires to a definition of health as follows:

> *"Health is a state of complete physical, mental and social well-being. In order to be healthy individuals or groups must be able to identify and realise aspirations, satisfy needs, change or cope with the environment. Health is seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasising social and personal resources, as well as, physical capacities" (WHO 1986, p.1).*

This definition of health embraces social, spiritual as well as biomedical contexts. The focus is on humanistic values, on aspirations and on transformation. Patient-centred care includes the wider and unique contexts of patients, for example their educational level, their priorities in life or their family situation. At the centre is the interpersonal relationship between clinicians and patients. Knowledge is generated in social contexts, informed by subjectivity and lived experiences. Patient-centred clinicians are mindful of the diversity in healthcare. Technical knowledge is only one aspect of professional practice knowledge. Higgs and Titchen (2001) claim that practice knowledge embraces propositional knowledge (technical), craft knowledge (professional experience) and personal knowledge (personal experience). They describe their conceptual framework of a professional practice according to four dimensions: people-centred, context-relevant, authentic (credibility and ethicality), and wise.

Patient-centredness reduces medical authority, but at the same time acknowledges the important role of science in healthcare practice. Patient-centredness seeks plurality between medical facts and people's values. The extent to which a patient is an equal partner varies within patient-centred approaches. Patient-centred approaches are concerned with imposing generalisable medical knowledge onto individual cases (Cox 1999). Values and priorities are not assumed but tested by discussing them with patients. Decisions for treatment management are made in collaboration with patients. Patients are seen as experts of their lived experiences in regards to health issues and clinicians are experts of their professional knowledge. Patients are respected as

knowledgeable partners. In their professional encounter patients and clinicians negotiate, collaborate and plan actions that are acceptable for both partners. Such a model advocates open-ended questions and strategic questions in order to elicit patients' perspectives. The focus of patient-centred approaches is to generate mutual understanding and find a common ground between clinicians and their patients. This focus is supported by social sciences paradigms that accept that multiple realities exist. The implications of a social science paradigm to healthcare community are:

Health is located in the social world

Practice knowledge is based on propositional, personal and craft knowledges

Physical, mental and spiritual aspects of patients are of interest and concern

Clinician-patient relationships acknowledge expertise of both

Evidence has a contextual, process-driven connotation

The implications for patient-centred patient education are:

Two-way information flow

Interactive approach to education

Clinicians exploring with patients what is best for them by providing relevant and realistic information

There are multiple realities

Technical knowledge represents only partial truth claims

Behaviour change is a complex process

Interventions are tailored to patients' contexts

Embracing diverse ways of knowing and doing

Within the social science paradigm humanity prevails over technology. Such a philosophical stance to health gives more power to patients and asks of clinicians to be mindful and respectful of other ways of knowing and doing.

Driving forces for a patient-centred approach are:

Providing realistic and efficient care

Conceding that uncertainty is part of clinical care

Reducing patient dissatisfaction and complaints

Empowering patients to help themselves and develop independence

Seeking explanations

Forwarding ideas

Stating preferences

Teaching methods include:

Informal

Participatory

Experiential

Reflective

Purpose of patient-centredness:

Patient empowerment

Effective self-care

Collective empowerment

Skills needed from clinicians are:

listening skills;

professional sensitivity; and

professional ability to negotiate decisions.

Skills needed from patients are:

ability to contribute to consultations; and

questioning skills.

Cochrane (Cochrane nd) sums up patient-centred care as:

> *defined as a philosophy of care that encourages: (a) shared control of the consultation, decisions about interventions or management of the health problems with the patient, and/or (b) a focus in the consultation on the patient as a whole person who has individual preferences situated within social contexts (in contrast to a focus in the consultation on a body part or disease).*

Emancipatory Patient Education

The emancipatory approach is rather foreign to patient education in hospital settings. Emancipatory approaches have been driven by:

Disability movement

Marginalised, voiceless groups (carer groups, youth groups, older people, gay community)

Community health

For some, a pluralistic approach to patient education doesn't go far enough to transform clinical practice in general and patient education in particular. Understanding each other's perspectives may not lead to mutually satisfying

decisions. The focus of this emancipatory approach is grounded in a belief in human capacity to reflect, change and improve current situations. Emancipatory patient education approaches make the complexity of power relations between clinicians and patients explicit.

Implications of an emancipatory model to patient education are:

Democratic qualities are needed,

Interactive clinician-patient relationship is consensual, not obligatory

Both parties are prepared to negotiate

Open relationship

Both parties benefit from the relationship

No hidden agenda

Local agreements are needed

A proliferation of diverse approaches

Transformation of relations between people at local levels

Profound change to patient education practice

A healthcare system that reimburses clinicians for their time spent dialoguing with patients

Such an emancipatory approach fosters patients to ask questions, not to unconditionally obey medical orders.

Comparison of three practice models of patient education

Table 1 Three practice models of patient education

Clinician-centred vs. Patient-centred approach			
Model	Medical	Negotiated	Emancipatory
Approach	Illness model Clinician-centred	Wellness model Patient-centred	Capacity model Patient-centred
Philosophical paradigm	Positivism	Realism	Idealism
Health definition	Reductionist	Holistic	Holistic
Focus of Health	Technical	Practical	Political
Role of patient	Passive, obedient	Interactive, participative but obedient	Interactive, participative, self determining

Action of patient	Comply	Participate	Liberate
Role of clinician	Teacher	Listener	Facilitator
Label for clinician	Task master	Coach	Critical companion
Power relations	Clinician has power	Clinician may share some power	Equal power sharing
Kind of interest	Technical	Practical	Emancipatory
Stance towards status quo	Taking things for granted, accepting, reinforcing	Being aware of taken-for-granted things	Challenging status quo and changing frameworks
Expectations by clinicians of patients	Not encouraged to think for themselves	Encouraged to think a bit for themselves	Learn to think for themselves
Patient power	Disempowered	Self-contained empowered (self-development-Feldenkrais)	Sustainable and collective empowerment (in a way that can be passed on)
Pedagogy	Traditional	Experiential	Critical
Patient education content	Out of context, objective facts	Within personal-social context, subjective values	Within political context, subjective reflected values
Context of decision-making	out of context	in psycho-cultural context (definitely not political)	In historic-political context
Clinician as helper	Helping to survive	Helping to cope	Helping to problem-solve
Knowledge	Propositional, technical	And subjective	And political
Clinicians' state of awareness of assumptions	Unreflective	Reflective with the aim to increase participation	Reflective with the aim to transform

Table 2 Comparative values between medical model and patient-centred approaches to patient education

	Medical Model	**Patient-centred Model**
Interest	Eliminating uncertainty, Evidence-based practice, Efficiency	Acknowledging uncertainty, Promoting health, Effectiveness
Outcome/aim	Increase patients' technical knowledge	Build on patient's existing knowledge
Content	Technical and factual	Social and realistic
Strategies	Identifying best option	Identifying choices
Power relations	Professional power	Patient power
Evaluation	Amount of technical knowledge	Amount of holistic knowledge

Table 3 Driving forces for a medical model and a patient-centred approach to patient education

Medical Model	**Patient-centred Model**
Economic rationalism	Socialism
Eliminating uncertainty	Embracing uncertainty
Evidence based movement	Promoting health movement
Empowering clinicians	Empowering patients
Efficiency	Effectiveness

Informing a Patient-Centred Approach to Patient Education

Reflecting, sharing, discussing practices are not common themes in healthcare practice. Clinicians are professionally socialised and often make decisions based on their assumptions about their patients. Clinicians are not encouraged to reflect on their practice, to debrief stressful situations and to focus on quality care for patients. Hospitals are not seen explicitly as learning environments but rather as intervention settings.

Further, there is a mentality amongst clinicians towards doing things to patients, having 'hands-on' versus 'hands-off'. Closely linked to this action driven approach is the idea of short-term care. Current healthcare politics encourage hospitals to have a high turn over and quick through put of patients. This is made worst by a chronic shortage of hospital staff which imposes time constraints to the delivery of patient education another barrier to providing patient-centred care. To be patient-centred means to many clinicians to take more time by listening to, being flexible about, negotiating and understanding patients' perspective. However, Smith (2002) argues that there is a need to not do things more efficiently in the health sector, but to do things differently. This means that in order to overcome the barriers mentioned above there is a need to shift the focus of the medical professional practice from a pure science approach to a people-centred approach (Higgs and Titchen 2001).

Popular education and CCD practices can help with this shift. They are advantageous if one is intent on facilitating a 'deeper' level of patient education and organisational change. If the aim is simply to acquaint patients with superficial facts and figures then straight information provision may be sufficient. But if one is intent on helping patients develop the capacity to make informed judgments, change behaviours or even critique and resist our consumer lifestyle, experience suggests that active and participatory learning activities will be more effective than didactic activities.

This suggests that to try and achieve these deeper levels of learning, patient education using a participatory approach can be supported by training clinicians in alternative approaches. This type of training would involve developing presentation and group facilitation skills. It would develop further the educational dimension of their health practice and help identify ways to plan experiences where patients learn through action.

Other Bodies of Knowledge

Forms & Traditions of Popular Education

It is useful to understand popular education in opposition to elite and excluding forms of knowledge. What is important to note is what popular education is not. It is not about making education simply more accessible to grassroots people. It is about designing education so that the knowledge, values and perspectives of grassroots people is privileged and shapes the curriculum. Traditions of popular education recognise and value what in contemporary Australian vernacular might be best called grassroots and frontline knowledge.

There is a key ambiguity and contestation in the history of popular education that continues to this day. There were then, as there are today, concerted efforts to make education more accessible to groups who, historically, had been excluded.

Such efforts were informed by a belief that there was a need to shift education from an elitist to a popular form. Yet, in many cases, it was perceived that education continued to be controlled by elitist interests and that it was simply being made more accessible.

The term highlights a concern for education that serves the interests of 'ordinary' people, as perceived by 'ordinary' people. An assumption is that there is invariably contestation about what will best serve their interests. The term is also underpinned by a notion of effective change practice which relies on being able to actively engage 'ordinary' people and to help increase levels of personal and collective efficacy.

The art and practice of struggling to build education for community action and grassroots democracy has a long and proud history. This art and practice is what this paper refers to as popular education. The notion of popular education has much to contribute to the efforts of those engaged in helping 'ordinary' people have more power and opportunity. This translates necessarily into education which is learner-centred rather than teacher-centred, which builds on the issues and experiences of the learners rather than a pre-packaged training course and which helps people understand their situation and act strategically.

Though this form and tradition of education does not have widespread currency and was not specifically designed for the hospital setting it is highly applicable to any situation where people may need to change behaviour and attitudes, but feel powerless to make that change which ultimately limits the likelihood of change occurring in the long term.

The term popular education is currently used by a small number of specialised research and advocacy groups though not necessarily under that explicit denomination. The concept of popular education is implicit in bodies of literature such as progressive and radical education, adult education for democracy and pedagogy of the oppressed.

What all bodies of literature mentioned above have in common is a concern with helping excluded majorities exercise acts of leadership in deciding what changes are needed in their own communities and lives. Critical and creative thinking is encouraged over acquisition of controlled knowledge.

Silver (1965) distinguishes between popular education that "aimed to produce a specific kind of man for a specific kind of role" (p. 236) from popular education that encourages people to oppose and imagine alternatives to the status quo. That second type of popular education invariably, according to Silver, leads to participation in social action. Johnson (1988) distinguishes between popular education that is concerned with useful learning, an individual activity that serves the interests of others, in most cases, employers, versus *really* useful learning that may be oppositional and supports independent and alternative analyses and actions. This last body of literature and practice highlights the value of examining questions related to control and whose interests are being served.

One body of literature that widely and explicitly uses the term 'popular education' is that which arises from the struggles of working class people in Europe and North America in the eighteenth and nineteenth centuries to develop education that was controlled by and for them. Another body of literature is that which emerged in Latin America in the 1960s-1970s (Crowther & Martin 1997, Arnold & Burke 1983a, 1983b and Arnold et al 1991) of which Paulo Freire is its best known exponent.

Freire has exerted an enormous influence on the practices and theories of educators who work, in particular, with people who are poor, oppressed and exploited. The value of the theories and practices inspired by Freire is in their focus on pedagogy, or ways to plan and facilitate learning. In the early 1960s Paulo Freire, in Brazil, developed an innovative approach to literacy education coined in his best known book *Pedagogy of the Oppressed* (Freire 1972b). He argued that educators should also help people to analyse their situation through discussions of basic problems they themselves are experiencing. As the causes of their problems are considered, the students analysed and discussed what actions could be taken to change their situation. Freire coined the term 'conscientization' to describe this type of learning. He suggested that the deepest educational challenge is to shift the way many people see themselves as recipients rather than makers of culture. Many people who have experienced social exclusion, poverty, discrimination and alienation in formal education, more often than not, have a negative self-assessment of their ability, let alone their right to influence change. They have low levels of self-efficacy and see themselves as objects of rather than subjects in history.

The traditions of popular education fall into a larger group of traditions that can be labelled progressive and radical education. An extensive body of literature describes the efforts of educators who have sought to (a) develop alternatives to dominant and authoritarian forms of education and (b) support the efforts of working class and community groups achieve some self-determination. Most of the progressive and radical education literature focuses on schools. It has, nonetheless, direct relevance to this discussion as it is characterised by a belief that people be given the opportunity to learn independently. It disagrees with the notion that education has a responsibility to mould and shape people (Simon 1972). Further, radical and progressive traditions believe in a learner-centred approach to education, in learners being regarded as subjects rather than objects of change and in facilitators rather than teachers.

In the tradition of adult education for democracy, both Lindeman (1933) and Kotinsky (1926) shared an interest in education that strengthened the capacities of people to participate in decision-making. A more famous educator of the time was John Dewey who also highlighted the challenge of educational practices to build people’s capacity for democracy.

The common features of popular education theories and practices include participatory learning, action learning and experiential learning. Underpinning the notions of participatory learning, action research and experiential learning is a broad conception of education and learning centred on the learner and based on techniques and processes of dialogue, problem-solving and praxis (action-reflection cycle). These techniques and processes are there to establish a continual spiral of reflection and action using a dialogical or 2-way learning methodology, where the learners and the facilitator are both facilitators and learners. The learning is located within the learners’ culture to bring about social change. This approach can be summarise as follows (Arnold & Burke 1983):

> Begin with the learners’ reality (to enable learners to formulate questions, identify key themes, issues and contradictions, share information and ideas)
>
> Reflect on that reality (to support learners voice their views and opinions about the world)
>
> Return to concrete action (act on their new found knowledge, in general, and their place in it, in particular).

Forms & Traditions of Community Cultural Development

CCD is a field which includes a wide range of practice from collaborative art to site specific art. But at its core it is about a local community collaborating with an artist in addressing issues of social justice and equal access. It is based on a desire to intervene with an intention to collaborate in making art and vice versa.

The field of practice that is CCD is ideologically based on principles of consensus work and democracy, but practically located within a spectrum of principles ranging from popular education to community development and cultural action. It "is characterized by its experiential and inclusive nature." (Lowe 2000, p.360).

The use of arts, be it theatre, song, writing, visual arts, dance, is seen as a practical and creative way to help people make and tell their stories. Popular educators, in general, are good at the facilitation of learning in this process as people author, produce, rehearse and perform their stories. That is why CCD has such relevance to popular education.

The field of CCD draws on Freire's notion of cultural action (Freire 1972a) Freire outlined a structured and practical pedagogy and practice to help bring about a profound shift in the consciousness of the 'oppressed'. He proposed that educators start by developing trigger materials that evoked learners' themes and issues such as generative words and a series of drawings. Educators used the drawings to provoke and create dialogue. It is a simple, but profoundly significant, teaching strategy. CCD has extended the use of drawings to other creative forms of storytelling and storymaking. In this field artists and community workers help people engage in struggle and make culture. This process lies at the heart of popular education.

The field of CCD in Australia has been very closely associated with the historical and political developments of the Australia Council for the Arts, the federal arts funding body. The trigger in Australia for the arts tackling issues of welfare and social justice can be traced back to the Whitlam Government's social policies emphasising 'access' and 'participation' and the establishment of a Community Arts Board within the Australia Council. With the renaming of the Community Arts Board to the Community Cultural Development Commission and a shift to 'empowerment', the field previously known as community arts became known as CCD (Clifford 1997).

CCD practices can be seen as events-that-model (Handelman 1990) defined as:

> A part or simplification and reduction of everyday life that behaves like the everyday life
>
> Contextual or done within a given situation and historical
>
> With a purpose and defined aims to change and procedures to make the change happen
>
> Self regulatory, with the capacity to monitor its own development and stage of procedures
>
> Having elements of conflicts that are solved as the processes unfold

McConachie (2001) sees these practices as a great medium for exploring possibilities or stretching the imagination of an ethical society or community and making meaning through community building. Further, Thiele and Marsden

(2002) found that their practice in CCD based in visual arts promotes cultural (i.e. social or group life skills such as cooperation, continuity, respect reliability and trust) connectedness and belonging referred to as "vertical process" as well as Cultural (i.e. art-making and creativity) participation referred to as "horizontal process".

The focus of CCD practices is on the process of behavioural and attitudinal change rather than on the quality of the product created itself. Haedicke and Tobin (2001) argue that the field of CCD in urban settings can be described as the kind of work that pursues a grounded functional aesthetics that goes hand in hand with social activism. It provides "a ritualistic setting for social interaction and [...] the construction of community" (Lowe 2000, p.357).

CCD practitioners work with people's experiences to create new learning experiences. They use art and creative tools and techniques to facilitate and enhance the learning experience, on the one hand, and draw on experiences located in the body and the mind to generate new learning, on the other. Further, the use of art or creative techniques allows for different ways of working. It is essential in that it offers "the possibility of envisioning something that might not even exist before" (Lowe 2001, p.463). "We know that the arts have the potential for obliterating the limits that are too often imposed on our lives" (Weitz in Lowe 2000, p.357).

The practices of CCD are inclusive, non-judgemental and don't focus on the need for people to improve their behaviour and take on more conventional attitudes and values in order to play a useful part in society, to benefit society (Cooper and White 1994).

The processes used in the field of CCD engage people in the planning, coordination and participation of creative projects (e.g. creative arts, story telling, films). It involves professional artists and 'ordinary' people working collaboratively within a reflective, experiential and action oriented context. This process of being creative and reflective can facilitate self-affirmation and self-assertiveness.

The principles underpinning the processes used in the field of CCD include:

People centred

Respectful and non-judgmental

Advocating for people's rights

Fostering social justice

Adopting reflective practices

Participatory, experiential learning approach

Action oriented.

There isn't one model of participatory practice nor a case for any participatory models being good practice. What seems to make good practice is the establishment of democratic structures with a catalytic individual allowing for open decision-making, responsiveness to local need, accountability to local people, attendance as well as participation within a clearly defined and ordered structure, clear project achievements 'something to show'. Good practice is one

which has a meaningful partnership, high quality experienced coordinators, staff and participants' enthusiasm and commitment and thorough monitoring and evaluation.

Comparison of conservative, popular and creative approaches to education

The following table of juxtapositions illustrates how popular education and CCD can be understood in opposition to dominant and conservative approaches to education.

Table 4 Juxtaposition of conservative, popular and creative approaches to education

Conservative education	**Popular Education**	**Community Cultural Development**
Learning through absorption	Learning in action	Learning through creative acts
Discipline, control and mandated learning	Democratic vision	Artistic vision
Top-down, professionalising and exclusive	Bottom-up, negotiated and inclusive	And non-judgemental
Pre-determined institutional and national goals	Problem solving and action	Problem solving and creation
Human capital development	Education for social capital	Education for cultural capital
Learning to be inspired	Learning to conspire	Learning to create
Education to meet needs	Education to champion rights	Education to make culture
Education for conforming with hegemonic ways of thinking	Education for resisting hegemonic ways of thinking	Education for devising other ways of thinking
Education to strengthen the capacity of elite leaders	Education to strengthen the capacity of grassroots leaders	Education to strengthen the capacity of grassroots community members
Education for individual leadership	Education for community leadership	Education for community leadership
Education for individual change	Education for social change	Education for cultural action
Education for powerful groups	Education for powerless groups	Education for powerless groups

Top-down education	Bottom-up education	Collaborative education
Education for private good	Education for the common good	Education for the common good
Education to help organizations control employees	Education to support self-help initiatives	Education to create sustainable initiatives
Education as validation of privilege	Mass education	Community education
Education as the great selector	Education as the great equaliser	Education through arts as the great equaliser
Education as methodology	Education as political and social action	Arts as political and social action
Education for individual achievement and empowerment	Education for community development and empowerment	Education for cultural development and empowerment
Education as technique	Education as passion and commitment	Education as creative process
Education for individual consumers	Education for community and nation	Education for community and culture
Education for social mobility, private life, consumerism, authority and order	Education for economic democracy and active citizenship	Education for artistic democracy and active citizenship
Education for self-directed learning	Education for participant-directed learning	Education for participant-directed learning
Education for skills development	Education for critical understanding	Education for critical understanding
Education for diffusion of knowledge	Education for reflection	Education for reflection
Education for autonomy	Education for social responsibility	Education for cultural responsibility
Consumer of education	Learner of education	creator of learning
Concern for technique	Concern for social context	Concern for cultural context

Benefits of using CCD in a clinical setting

Contextualising CCD in clinical settings

Arts in Health is a wide field of practice which varies from contributing to the healing process (art therapy), to creating a healing environment (public and performing arts as distraction), caring for caregivers (participating in the arts as a rejuvenating exercise), supporting access the arts for people living with disabilities (arts opportunities or outreach to facilitate self expression and personal growth), enriching the medical curriculum (arts and humanities in the curriculum to balance the purely clinical approach to health) and / or helping communities in times of crisis (CCD type of group work to cope with trauma, grief and loss as well as celebrate solidarity) (Palmer 2001 and Holmstrom 1996)

Chambers' (1998) premise on health is that it is an outcome of a process of participation which the arts can help with. There is an assumption that "the integration of the arts and humanities in healthcare delivery systems is essential to ensure a compassionate and humanistic patient and family care." (Bailey et al 2000, p.366).

The use of arts in health can add to people's value and foster meaning to clinical practice (Maxwell and Winning 2002). A CCD approach at POWH can assist staff, patients and its wider community to create a more culturally appropriate and sensitive hospital environment. This non-judgmental and creative approach can foster improved rapport and interpersonal communication (Titchen and Higgs 2001).

The *Art for Health* report (SMH 2000) concludes that the link between arts and health is one of participation "engendering a sense of social inclusion" (p.24). Also, the ABS report (ABS 2001) states that "health may be optimised when an individual is able to balance passive and active leisure." At a social level, "activities that actively analyse, develop and challenge our cultural norms are crucial to social wellbeing and sustained development [...] new meanings generated by arts activities help us to adjust to change and to understand our society." Further stating that "The reflections of social and individual experience found in art and other forms of culture assist groups to share and integrate their life experiences."

The world symposium held in Manchester in 1999 on *Culture, Health and the Arts* discussed 3 broad areas for the use of arts in healthcare including "humanising the education of health-care professionals; improving the quality of care provided to patients in health-care settings; and developing healthier communities." (Martin 1999, p.1451)

Generally speaking, the field defined by the term arts in hospitals includes practices which create a place or improves the aesthetics of a place through the use of design, architecture, landscaping, occupational therapy, cultural planning (collaboration between artists and architects in hospitals) and public arts to distract by creating a soothing environment (Meyrick 2001, Ridenour 1998, Scher and Senior 2000 and Holmstrom 1996).

Art therapy is the use of creativity to treat a pathology or labelled condition (corrective or complementary treatment) with a clinical aim. This treatment is controlled by the clinicians and the activities are organised according to medical goals (Clifford 1997).

The field of practice we are concerned with here, though, is the use of CCD in a healthcare setting, a participatory approach to health and wellbeing focused on working with the whole person to help them create and transform a space outside of the illness focused world they inhabit. The activities are a collaboration between artist and participant with artistic goals (Clifford 1997). This is more common in community health settings, though appearing more and more in clinical settings as an evolution from public arts in hospitals. This has been brought about through a shift in belief from the need to have a passive appreciation to being active in the arts (Ridenour 1998).

Through participation in the arts patients are empowered to take control in the decision making process of their wellbeing or treatment. In this context art is seen as a powerful tool to build and consult communities and give voice to socially excluded groups (Meyrick 2001). Through participation in the arts clinicians can be trained to promote empathy and communication with their patients (Meyrick 2001).

Ball and Keating (2002) argue that participation in the arts has no power to heal the "growing divide in our society", but has "the capacity to heal, to question, to challenge, to connect, to celebrate, to empower, to reflect and indeed to be an agent for beneficial social change." Participation in the arts will not improve a patient's health, but good facilitation of participation in the arts will enhance the learning experience in relation to health. Smith (2002) suggests that participation in the arts would help not in winning the battle against suffering, sickness and death but in helping us learn something about pain and "adaptation, understanding and acceptance" (p.1433).

Ways in which CCD can enhance patient-centred care and education

Hospitals are made of diverse groups of people with different values, histories, beliefs, opinions, languages and cultures temporarily brought together to form a heterogeneous community based on some material circumstances, health issues and facilities. We have previously argued that this temporary alliance can be best tackled through a patient-centred approach rather than a purely scientific or empirico-analytical approach.

The following discussion highlights ways in which CCD can enhance patient-centred care and education. We argue that CCD processes can help make clinicians practice people-centred, context relevant, authentic and wise.

People-centred

Higgs and Titchen (2001) define a people-centred practice as one that works with, and for, people to enhance, empower and develop their lives and environments. It opposes the depersonalisation and quantification of care to focus on quality or gracefulness of care. People-centred care requires professionals to hear their patients' voices. It therefore requires a critical approach to education, practice, research and practice development.

Establishing a dialogue between clinicians and patients is core to developing a people-centred practice. This requires building a relationship between clinicians and patients whereby the patient's interests and imagination are captured and engaged. This occurs by allowing patients to express their experiences rather than place them in a position of passive observer.

CCD practitioners facilitate dialogue by working with individuals and groups at providing a channel for their stories and a medium for self-expression, critical

thinking, problem-solving, decision-making and empowerment by using various artforms as tools free of negative learning experiences, judgment or trauma. This non-judgmental and creative approach can improve rapport, and interpersonal verbal and non-verbal communication (Titchen and Higgs, 2001).

There are an infinite variety of ways of engaging with and fostering participation of patients. Depending on patients' interests and level of attention the CCD practitioner makes some practical choices to encourage the sharing of experiences and thoughts. As Wiley and Feiner (2001) found when researching the use of theatre as a CCD process, "When a group of people comes together to decide what stories to tell and how to tell them, they engage in a formal definition of *culture* [italics in the text] (...) as they negotiated their playmaking, they are also negotiating community identity and culture" (p 125).

Context relevant

The need for care that is context-relevant comes from the recognition that the world is ever changing and complex. This point emphasises the importance of looking at situations from an international, national and local perspective as well as a historical, social and cultural perspective for the patients as well as for the clinicians (Higgs and Titchen 2001).

CCD as a model of practice is couched in a cultural approach, cultural context and cultural way of working. It seeks to generate collaborative art that is both in content and form relevant to the participants, their lifestyles, cultural beliefs and geographical location.

CCD practitioners do not presume to know what people feel, think or know. The philosophy behind this kind of site or context specific work is not to use people's experiences as a backdrop, but to use people's experiences as an integral, functional and active part of the material to be worked with in order to validate people's lives and create a reflective experience.

Since practitioners value people's experiences and the practice is an acknowledgement of people's experiences and lives, CCD processes can only begin by determining the context of the individuals or groups that will engage in the practice.

Authentic

Authenticity of a patient-centred care and education is defined by Higgs and Titchen (2001) as a professional practice that is credible, has authority (power) and is accountable (based in ethics, morals and realities).

In the field of CCD, authenticity is understood as community self-representation or representational authority (Wiley and Feiner 2001). CCD practitioners bring people together to directly have an experience of being creative and help them shape something that they're actually involved in with what they know, who they are and what they do. As a consequence, CCD outcomes speak powerfully and authentically about participants' experiences because of that involvement in shaping its social and cultural references, narrative, language and tone.

CCD projects as public events are human constructions. They are cultural, historical and logical phenomena that index social order. They function as community or relationship building exercises between individuals and social order to present aspects of the participants' lived-in world. They are a world within a

world, a "media through which members communicate to themselves in concert about the characters of their collectivities." (Handelman 1990, p.15)

Wise

A wise practice is a practice which enables the exploration of other ways of knowing, doing, being and becoming. This means a practice that generates knowledge through critique and debate as well as one that is transforming. "Practice wisdoms considers not just the best of what is, but the broader possibilities of what could be." (Higgs and Titchen 2001, p.11).

Intrinsically, a creative endeavour uses everything individuals or groups know about their being, from really practical and physical things, to their sense of deception and socialising skills. CCD practices really engage with and give people a sense of meaning and being by generating new understandings about people's world. As Wiley and Feiner state "[CCD based] theatre is a way of increasing or enhancing our understanding and sense making of those symbols [that define culture]" (p.125). Hence, CCD practices can create an environment which bridges the cultural divide between patients and clinicians.

CCD projects as public events are a concentration of symbols usually diluted in the every day life which can help bring something absent into being. "Their mandatel is to engage in the ordering of ideas, people, and things." (Handelman 1990, p.16). They are devices of praxis merging "the ideal and the real, to bring into close conjunction ideology, practice, attitude and action." (ibid).

Common ground between patient-centred care, popular education and CCD

The literature review on patient-centred care, popular education and CCD crystallised the following common grounds (see table 5). All accept multiple realities, focus beyond bio-medical health issues and practice in collaboration, participation and context of their clients.

Table 5 Common attributes of patient-centred care, popular education and CCD

Attributes	**Patient-centred care**	**Popular education**	**CCD**
People-centred	Patient centred	Knower centred	Participant centred
What is credible knowledge?	Including patient knowledge	Excluded majority knowledge	Spect-actor knowledge
Ways of generating knowledge	Professional craft knowledge	Cognitive praxis	Creative praxis
Focus	Health	Democracy	Voice
Aim	Improved health care delivery	Transformation from object to agent	Reclaiming creativity

Relationships	Collaborative	Collaborative	Collaborative
Context is inclusive	Psycho-social	Political	Social-creative

Future Steps and Challenges

As a direct outcome of this discussion paper, the POWH intends to pilot a project that adopts a CCD approach to diversity health issues in patient education that is people-centred, mindful of people's rights, creative, participatory, reflective and action-oriented. The following section makes recommendations for this CCD pilot project based on the results of a discussion and comments made by health practitioners at a roundtable convened by the Diversity Health Department and the Centre for Popular Education in June 2003. These recommendations are for a pilot project lead by a professional artist to address diversity health issues in patient education practice with a main focus on integrating patients' perceptions and experiences of their health problems into effective and culturally competent patient education. The recommendation is also for an initiative confined to a hospital setting though there is also scope to work within communities at a later stage, as this approach is ideally suited to preventive health strategies.

Processes and constraints

Imagine an artist experienced in CCD practices employed by POWH's diversity health department over a three-month period to work on the wards in collaboration with patients and clinicians for between 1 to 2 hours a week using a given artform, such as cartoons, photography or writing. Imagine how creative expression might help facilitate the work of a clinician by improving patients' learning with an artist working on the mental health ward, collaborating with patients and clinicians (nurses, doctors and consumer advocates) using theatre to develop and perform a script or an artist working in oncology, using photography to collaborate with patients and clinicians on producing photo-essays for an exhibition.

This pilot project would help create a more conducive learning experience and environment. It would provide the opportunity and a context for health condition and treatment options to be discussed, for clinician-patient relationships to be grounded in mutual respect, for a two-way education between patients and clinicians, for a strengthening of links between local community health services and hospitals, for an arena to discuss how health professionals and patients see their respective roles, to give back control taken away by a diagnosis, etc.

First though, there are some specific constraints or barriers to education and care associated with working in hospital settings and the effect they might have on achieving the outcomes and sustainability of such a project that we need to be aware of. They are constraints around the kind of community, health problems, length of time, level of investment by staff and patients, cultural expectations, etc. that a CCD practitioner can expect to have to work with in a hospital setting.

In order to improve care and education of patients there is a need to work with the clinicians. Therefore, there is a need for health professionals to be introduced to CCD practices. Yet, we also know that the care required for patients is high and clinicians are already overworked. They are also used to seeing similar alternative projects come and go and expect limited continuity and benefit for their work. This means that more thought about what can be done for them and collaboration needs to be put into the pilot project in order to get a positive response from the clinicians.

Another limitation, which comes from working within this setting, is one of definition of community. In a major metropolitan hospital the community or group an artist is likely to work with would be one based on a temporary alliance

between patients on very short stay often from culturally diverse backgrounds and busy and transient clinicians. This is, in effect, in conflict with the practice of CCD as a long-term preventative approach. Further consequences of this constraint would be the difficulties in determining a collective rather than an individual relevance. This is not an unsurmountable obstacle, but would be a limit to the extent to which this practice would be a true collective and collaborative effort.

Further, the fact that at POWH a majority of the patient population is from a culturally diverse background would require the use of an interpreter during some of the sessions.

Yet another constraint is the need for such a project not to focus on the dissemination of information because in most cases patients experience information overload. Clinicians feel compelled to deliver huge amounts of information in very short periods of time. This is compounded by the fact that often patients are anxious, they are not well enough to learn, there is too short a time to process the information and some might even be there against their will (eg under the mental health act), therefore not be prepared to hear what the clinicians say. This usually means that two weeks later patients only remember little of the information about their diagnosis, treatment or medication.

The choice of clinical setting (e.g. primary healthcare, acute, long-term, mental, etc.) will also bring with it a specific set of difficulties and limitations. This means that the chosen CCD practitioner will need to work very closely with patients and clinicians' input in working around availability and workflow of the various units and services within the hospital.

Finally, ethical issues around the processes and the art produced would need to be addressed. Approval should be sought and obtained from management, clinicians and patients to ensure confidentiality and anonymity, protection from disclosure as well as issues of ownership.

To this end, the authors recommend that a professional writer experienced in CCD should be employed by POWH's Diversity Health Department to engage with patients and clinicians in a creative practice to address patient education. This project would build and extend on the knowledge and experiences of the participants focusing on issues and problems that are particular to the two respective groups. Value should be placed on the patients as well as on the clinicians' knowledge and perspectives as experts. This would lay the groundwork for building a whole-of-community approach to analysing and acting on chosen health education and care issues where CCD processes would be used as a medium for both clinicians and patients to express their diversity and make their health beliefs, priorities and professional or personal perceptions about disease explicit in a safe and non-judgmental environment. The engagement would emphasise participation, learner-focus, and collaboration. The products will be used as educational material for clinicians and patients as well as a quality art product that can be displayed in the ward.

Objectives

This project would have for objective to address diversity health issues in patient education at POWH. It would provide an opportunity for POWH to take up one of its key challenges, which is to meaningfully engage with diverse patients to foster their sense of wellbeing, and self-control over their health.

This project would build and extend on the knowledge and experiences of the participating patients and clinicians. There would be a focus on issues and problems that are particular to the two respective groups, such as the tensions and conflicts between specific areas of knowledge, which is dependent on the clinical area where the project would be based (e.g. cardiac, mental, etc.) and skills. Value would be placed on the patients as well as on the clinicians' knowledge and perspectives.

The priority health issue to be addressed would therefore be one of service development, focusing on rehabilitation through improved communication and service delivery models.

The aim of this project would be to:

Change the balance of power between clinicians and patients

Change the hospital culture and dynamics between doctors and nurses to a more equal collaboration

Enhance the level of discussion and control in the decision-making process by the patients by increasing patients' understanding of the options in treatment and rehabilitation

Improve the hospital's health performance indicator by increasing the patient's sense of satisfaction with the level of health care provided

Improve understanding and access to patient education resources

Improve the way clinicians feel about the way education and care is delivered

Increase the use and effectiveness of communication strategies (listening, questioning, body language…) through hands on activities

Strengthen the relationship between patients, family and professionals towards self-management

Bring patient education and patient care together

Ultimately, a CCD project would help achieve quality health care outcomes by working on the hospital's cultural setting and exploring the 'human potential' in the patients-clinicians relationship.

Outcomes

We would expect the outcomes for participants in this project to be many fold, some short and others long-term. These might include:

Professional development for clinicians in patient-centred education and care. A stronger commitment and interest in patient-centred education; an improved delivery of appropriate and efficient, learner-centred patient education to their patients; an enhanced awareness and improved skills of clinicians regarding the complexities of appropriate and efficient patient-centred care; stronger and energised staff.

Quality health learning outcomes for patients. An opportunity to be heard and to express themselves; an increased level of understanding of their health problems, results and treatments; an increased understanding of the importance of their participation in recovery and rehabilitation; strengthened capacity in patients and their families in looking after their health.

Enhanced patient-clinician relationship and communication. An increased awareness of each others' perspective; an increased understanding of more appropriate, efficient and effective ways of communicating; an opportunity to care through education and vice versa; an opportunity to humanise and strengthen the relationship between patients, family, community and health care professionals towards better understanding, mutual respect and trust.

Production of a quality art. With the possibility of it being displayed or performed in the hospital for a short period of time or acquired by the hospital to be displayed on a long-term basis. This would need to be determined in accordance with advice and suggestions sought from the art group of the POWH.

Development of educational material for ongoing patient–centred education. To ensure sustainability the processes and product need to be developed into an educational package that can be used with future patients and clinicians in patient-centred education and service development to be used in regular workshops.

Evaluation

A challenge for this project will be to produce an evaluation which will:

Document and monitor the progress of the project.

Describe a best practice model for CCD projects in clinical settings to be repeated throughout the 40+ specialties of the POWH, in the first instance and nationwide, later.

Provide detailed indicators to help measure the extent to which CCD in clinical settings works in bringing about learning and change in behaviour and attitudes.

What will inform the choice of evaluation methodology and framework? Often, evidence that has not been tested within an empirical study is rejected. Medical facts, quantitative data, evidence-based practice (EBP) are seen as the hard evidence. The biophysical aspects rank very high whereas psychological, social and political aspects of health rank very low and as such are seen as soft evidence. Yet, the processes of patient-centred care cannot be captured in empirico-analytical approaches alone although it can produce some evidential outcomes. An empirico-analytical position to evaluation should therefore not be imposed on an interpretive-critical position to evaluation as there is a mismatch of worldviews (working paradigms). EBP is outcome and efficiency driven whereas interpretive-critical positions are process driven.

The description, documentation and monitoring of this project should be based on methodologies including fieldwork and ongoing liaison with all stakeholders. The data should be collected from both participants and practitioners using focus

group discussions, interviews (face to face and telephone) and observation. Regular project meetings could be convened to ensure that the various stages of the project are proceeding according to the guidelines and timeframe agreed upon between the artist and the hospital. The evaluation should also focus on patients and clinicians' views and opinions on the processes used and product generated, providing them with a structured method for helping them reflect on their experiences and actions in order to process their learning.

To measure the impact of the use of CCD strategies to inform a shift to patient-centred care and education in hospital settings, we need to look for evidence and indicators of change such as improved wellbeing, sociability, self-esteem, personal development, confidence, education and awareness (SMH 2000) or evidence of the impact on patients in term of personal development (identity, confidence and sense of self-worth, developing social trust and skill development, employment and educational benefits) as well as community development (social cohesion, bringing people together, local image and identity and community capacity building) (Ball and Keating 2002).

Another useful model for measuring the impact of the patient-centred care and education was developed by the Centre for Health Promotion of the University of Toronto. Their quality of life model (QOL) also emphasises the social determinants of health and wellbeing. The model is based on 3 domains -Being, Belonging and Becoming- each with sub-domains -physical, psychological and spiritual being, physical, social and community belonging and practical, leisure and growth becoming- determined on levels of importance and enjoyment and based on the quality of environment a person or group lives. The quality of an environment is determined by the level of provision for basic needs, range of opportunities and control / choice / decision-making. From this model the Centre for Health Promotion has developed a profile which consists of 54 items, 6 in each 9 sub-domains within which importance and enjoyment as well as control and opportunities are rated from 0 to 5 (Raphael 1998).

Conclusion

There is recognition that there is much to do to improve patient-centred education and care. The aim of this discussion paper was to make a contribution to patient education by exploring alternatives, such as CCD, to didactic forms of education. The authors argue that CCD practices have a lot to offer as it provides a potential for an integration of patient education and care practices, patients and clinicians communication and ways of facilitating effective and culturally competent patient-centred education and care.

Drawing on traditions of community cultural development and popular education, the authors discussed the possibilities of using the cultural experiences of patients and health care practitioners to inform patient education materials and practices. This paper reviewed literature that constructs culture as an asset rather than as a barrier in patient education and crystallised common values of CCD, patient-centred care, popular education and diversity health. Cultural experience directly shapes what and how people learn. Therefore, good education practice should engage with it. To help patient-educators engage with cultural experiences they need highly developed questioning and listening skills. Important aids for the questioning and listening processes are accounts of cultural experiences.

Based on the recommendations within, further discussion with POWH management and clinicians needs to be carried out to plan the logistics of the project, identify appropriate locations for implementation and determine the artforms and type of collaboration to be pursued.

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Appendix

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