FROM THE THIRD GENEVA CONFERENCE ON PERSON-CENTERED MEDICINE: IN REVIEW

Tailoring care to individuals and populations within resourcepoor settings: A review and commentary on the World Health Organisation Report *People-Centred Care in Low and Middle Income Countries*

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Introduction

The comprehensive definition of health articulated by the World Health Organisation (WHO) and incorporated into its Constitution in 1946 [1] had a profound impact on the international understanding of health and disease, informing a wide range of health services research and development initiatives and giving great momentum to the prevention and treatment of ill health and to the promotion of positive health globally [2,3]. WHO's growing interest in the individualisation of health care [4] and in a more effective tailoring of care to communities has led to a series of important resolutions and publications, most recently illustrated, perhaps, by the 2007 Reports People Centred Health Care [5] and People at the Centre of Health Care [6], by the 2008 Report Primary Health Care: Now More Than Ever [7] and, most signally, by the relevant resolutions of the WHO World Health Assembly in 2009 [8]. As a result of these particular actions and the impetus provided by the International Network for Person-Centered Medicine (INPCM), much progress has been made in the articulation and implementation of personcentered clinical medicine and people-centered public health in the Developed World [9-12].

But what of the situation in low and middle income countries? How much progress has been made there and

what can be done to accelerate the development of people and person-centered care in those geographical areas where resource constraints (as increasingly in high income countries) and sometimes a resistance to innovation and change (again, as in the West), militate against the organisation and delivery of efficient and integrated clinical services? It is precisely these questions which were posed - and addressed - in a meeting organised as part of the Third Geneva Conference on Person-Centered Medicine, co-ordinated by the INPCM and held at the headquarters of the World Health Organisation on 5 May The presentations that were made and the discussions that took place were wide ranging and informative and congratulations are certainly due to Dr. Wim Van Lerberghe, WHO Director of Health System Governance and Service Delivery and Dr. Carissa Etienne, Assistant Director General, Health Systems and Services of the WHO, for their overall direction of the meeting and in coordinating the publication of the subsequent report People Centred Care in Low and Middle Income Countries [13]. In this short article, a review of the essence of the WHO Report [13] is presented to readers of this inaugural edition of the International Journal of Person-Centered Medicine, with the aim of summarising the content and conclusions of the Report [13] and offering some suggestions on how further progress might be achieved.

Tailoring care to Individuals and communities

People-centered care has been defined in various ways, but common understandings articulate it as a type of care which is focussed on and organised around given groups of people, rather than on the disease alone, in isolation from While it is axiomatic that the broader concerns. scientifically-informed prevention and treatment of disease remain of fundamental importance, they far from equate to the overall goal of people-centered care which, rather, aims to address the needs and expectations of individual people within the context of their communities, so that family, friends, community, values, knowledge and culture remain of pivotal conceptual and practical importance. Here, the prioritization of people's experiences of their health and illness by health workers are considered alongside the circumstances of their everyday lives, ensuring that proper understandings of patients', families' and communities' perspectives and choices are elicited, heard, respected and employed in the design and delivery of clinical services. People-centered care is therefore more epidemiological, rather than directly Hippocratic in nature, but in its practice and for the reasons given, would incorrectly be identified simply with what has been described as the impersonal approach of traditional public health thinking and intervention. On the contrary, properly understood, people-centered health care and person-centered health care are two concepts and practices that can be seen to be conceptually and practically complementary, rather than in any way antagonistic, both representing powerful approaches to the provision of scientifically informed care within an entirely necessary humanistic framework [14]. This is precisely how the WHO Report [13], in accordance with previous WHO publications [3-9], understands their relationship.

Implementing people-centered care in low and middle-income countries

The pattern of implementation of people-centered care in low and middle income countries has been varied, with both 'top down' and 'bottom up' approaches observed. The so-called 'top down' approaches have been characterised by the formulation of national policies with definitive commitment to implementation from holders of political office and senior government officials, whereas examples of 'bottom up' approaches include modestly conceived demonstration projects which have then been replicated elsewhere within the same country. Some projects have concentrated on very specific health issues, whereas others have focussed upon more comprehensive coverage, aiming at the introduction of people-centered approaches across a wider spectrum of health services. In illustration of the differing initiatives being taken within the developing

world, the WHO Report [13] usefully discusses the progress achieved by five, specific countries: El Salvador, Malaysia, Rwanda, Thailand and the United Republic of Tanzania, based on the presentations made at the 5 May 2010 session of the Third Geneva Conference.

El Salvador

The example provided from El Salvador focuses on maternal mortality which, according to WHO estimates, stands at 170 per 100,000 live births [15], a rate considerably higher than the regional average of 100/100,000 and with deficiencies in the quality of maternal health services as well as significant social and economic disadvantage suggested as causative. These statistics stimulated a governmental people-centered medicine initiative, involving both national and local leaders within the health system, with the aim of enhancing access to maternal health services and increasing the empowerment of women, their partners, families and communities. Methodologically, the initiative commenced through a process of team building within the health system at national, regional and departmental levels, followed by the creation of strategic committees formed with representation from municipal government, local institutions, non-governmental organisations, health workers and communities themselves. Community consultations followed, with separate for aheld for women of childbearing age, importantly including their partners, mothers, mothers-in-law, grandmothers, health workers and community and indeed religious leaders. recommendations made by these fora were then assimilated by an inter-stakeholder forum at which common themes were identified and a consensus formulated on the most urgent priorities, with a formal consideration of how action plans could be drawn up and implemented with an expectation of reduced maternal and neonatal mortality and morbidity.

Encouragingly, the developed programme has been implemented operationally within eight municipalities at the time of writing and although the consultation process described above was standardised across them, interesting differences were observed in the way in which each municipality subsequently customised the programme in alignment to its particular individual context and local priorities. Remarkably, maternal deaths are reported to have decreased to zero since 2006 in 90% of the municipalities participating in the programme and a further benefit of the development and implementation process has been a greatly enhanced sense of ownership within the communities and a growing leadership within them, so that people's relationship with their local health service has improved significantly and intersectoral links and mechanisms of coordination have additionally been strengthened. The programme continues to promote people-centered care by actively informing the development of national policies, recently becoming accepted for inclusion within the El Salvador national plan for the reduction of maternal, perinatal and neonatal mortality and the national plan for social participation.

Malaysia

A similar example of encouraging success in the development and operation of people-centered medicine policies and practices and documented within the WHO Report [13] has been supplied by Malaysia, a populous country of some 27 million people with a definitive *person focus* prominent within the country's stated national health service goals. This policy currently translates into an emphasis on wellness, a commitment to the availability and provision of accurate and timely health information, processes for the empowerment of people in the selfmanagement of their health, together with tailored and integrated health services provided locally and universal access to primary care services at minimal direct cost – the Report [13] quotes the US dollar equivalent of \$0.30 for each outpatient visit.

Further examples of the commitment of the Malaysian Ministry of Health to the promotion of people-centered care recorded by the Report [13] are provided by its introduction into practice of a set of innovations aimed at the improvement of the quality of care which include the availability of home-based health cards allowing inhabitants of more rural and remote areas of Malaysia to have access to their health records and to obtain health care at any facility. The creation of an on-line 'my health eportal' is additionally documented. Further initiatives include the availability of electronic lifetime health records and also the extension of clinic hours with the aim of making service availability and attendance opportunities more convenient for patients, with home attendances increasingly possible in some areas for children and studies underway evaluating the benefits of postal delivery of medications and drive-through pharmacies.

A noteworthy additional set of innovations has been governmental action resulting in the introduction of practice guidelines, credentialing and privileging, continuing professional development programmes and systems for patient and family feedback on their experience of care. These mechanisms appear set to improve the overall quality of clinical care as part of a determination by the Malaysian government to increase the professionalism of health care workers and of the standard and extent of caring in general.

Rwanda

Having recorded these developments in El Salvador and Malaysia, the WHO Report [13] continues by reviewing the innovations introduced and progress made in Rwanda. Psychiatric and psychological morbidity in Rwanda is high, with rates of depressive illness and post-traumatic stress disorder that are greatly in excess of national

averages elsewhere, disturbances which are perhaps most easily understood in terms of the effects of the 1994 genocide on the collective conscience of the remaining people. In order to address this problem, the Government of Rwanda instituted a programme aimed at the provision of people-centered health care to all those citizens presenting with mental health problems.

An initial national mental health policy was agreed shortly following the cessation of violence in 1995, with officials and others proceeding some ten years later in 2005 to the prioritisation of mental health as a major area for health intervention, calling additionally for the integration of mental health services in all national health system structures and at the community level. At the time of writing of the WHO Report [13], a decentralisation of mental health services had taken place, such that 41 of 43 district hospitals in Rwanda now operate mental health care services.

Moreover, success has been achieved in the methods used for drawing up personalised mental health care plans, with care provided as close to people's homes as practicably possible. Importantly, trained nurses, acting under medical supervision, now contribute to the delivery of clinical services and, from a governance and audit point of view, participate regularly in individual case review sessions along with other mental health workers, including medical students. A key feature, and one emblematic of the people-centered approach being taken in Rwanda, is the management of mental disorders from the biopsychosocial and holistic perspective. Thus, people presenting with psychological dysfunction or frank psychiatric illness are considered not simply in terms of their diagnostic category, but rather in terms of their history, community and indeed their current life circumstances, with efforts currently underway to integrate mental health services with general health services. The support of family structures is emphasised here, such that the Rwandan National Mental Health Programme is clear that 'families are our partners in the health care business; everything is done with them'.

Thailand

Having considered the status of people-centered care in Rwanda, the WHO Report [13] moves to a review of the position in Thailand, a country which has recently modified the model of its health services delivery from one built essentially entirely on a secondary care model to one now organised principally in and from the community. Historically, the move within Thailand to people-centered care began in 1991, following the initiative of a small group of health services researchers demonstrating, over a range of different health facilities, that people-centered approaches to care were not only possible to implement, but indeed preferable to the prevailing system.

Methodologically, regular community consultation aimed at eliciting people's views was followed by a more

systematic utilisation of patient and family records, the construction and use of registries for clinical populations and the introduction of improvements in referral systems between primary and secondary care facilities, together with a greater use of home visits and the use of a payment system based on flat rates per illness episode. A measure of consolidation was achieved by disseminating knowledge of the innovations across health services and networks and by introducing the relevant training into pre-service nursing and medical curricula.

This 'bottom up' approach to the implementation of people-centered medicine was commended to the political classes of Thailand via the organisation of visits by the Minister of Health and other relevant officials to the reorganised and developed health facilities, where direct observation of the successful operation of the new model of care was possible. In this way, political interest and support was developed strategically to the extent that, following the publication of Thailand's universal coverage reforms of 2001, the people-centered approach was adopted by the government as the foundational model for its primary care-based health care system.

The associated statistics are illustrative. Indeed, within a one year period, the people-centered programme had extended from 60 health centres serving some 60,000 inhabitants to 1164 health centres, serving some 12 million people.

Tanzania

The final example presented at the Third Geneva Conference and discussed in the WHO Report [13] is provided by the United Republic of Tanzania and takes the form of a project designed specifically to improve the care of people receiving anti-retroviral therapy (ART) by assisting the adherence of HIV-infected individuals to their anti-retroviral regimens with the aim of securing the best clinical outcomes possible in terms of morbidity and mortality from infection and disease. The rationale for the project derived from baseline analyses which had reported that up to 36% of patients routinely missed their clinical appointments in any one month, raising serious concerns about the effects of treatment interruption on individual and public health. At the time of writing of the WHO Report [13], six health centres are in the process of implementing the aims of the project, with a subsequent extension planned to enable the coverage of the entire region and thus some 2 Million inhabitants.

The development of the people-centered health care approach commenced with the identification, through convened focus groups consisting of local people, of the common barriers to clinical attendance and how such difficulties might be overcome. The barriers described were simple, yet fundamental: the availability (or lack of it) of transport to and from the clinic centres and the fear of stigma and discrimination associated with being seen as an attendee at the clinics. Through the direct elicitation and

use of patients' own solutions to these logistic and cultural barriers to clinic attendance and drug regimen adherence, the health services researchers were able to reconfigure existing services to take account of people's needs and to modify health worker – patient interactions. For example, the quantity of antiretroviral drugs dispensed was increased to a two month supply to reduce the frequency of clinical attendances required and relatives were permitted to collect anti-retroviral drugs on behalf of patients in order to attenuate the patient's fear of being identified as a clinic attendee, with measures additionally taken to enhance the privacy of the anti-retroviral clinic facilities themselves.

Shared decision making processes were also introduced within clinic facilities, so that consultations no longer involved the handing down of paternalistic treatment decisions and instructions, but rather became characterised by patient involvement in decision making and their active participation in the planning of their care. Although health care workers were initially resistant to the changes described, audit of progress demonstrated a growing satisfaction with the quality of care by both health care workers and patients and the demand for reconfigured services is reported to have increased threefold, posing operational challenges of its own. Notwithstanding these, the Tanzanian Ministry of Health and Social Welfare is currently in the process of developing quality improvement guidelines and training manuals to assist the dissemination of the innovations described to other areas within the country.

What lessons may be learned from the specific projects discussed?

A key feature of the WHO Report [13] is the section which discusses the lessons that can be learned from the experiences described in the five countries studied and which identifies a series of factors that appear to be of methodological utility in the development of peoplecentered health care within the given contexts. The Report [13]recognises that action at multiple levels, not just a single level, is required to ensure the progress and ultimate success of people-centered approaches to care and that these will include modifications in the health worker – patient interaction and relationship, reconfiguration of clinical service organisation and delivery, the involvement of the local community and, very importantly, political commitment.

The Report [13] observes personal interactions as fundamental to success. Here, regular communication with patients and their families and the building of close relationships with community organisations such as non-governmental agencies, community health workers, volunteers, self-help groups, schools and employers was viewed essential, so that knowledge and trust is established and patient feedback made available for use in the development of services. Not that professional

engagement with this philosophy was automatic. On the contrary, in the examples described within the Report [13], initial professional resistance to a modification of service delivery that incorporated these principles was a recurring feature and health care workers typically required direct evidence that the active participation of patients in their care - and the time taken away from busy schedules required to build and maintain personal relationships and to take proper account of patients' preferences, values and expressed needs and to encourage health promotion, disease prevention and risk reduction - was useful and likely to lead to better clinical and related outcomes. Likewise, the use of methods designed to ensure continuity of care through decentralisation of clinical services and the proper functioning of referral systems were seen as vital, with primary healthcare teams viewed as ideally suited to the implementation and use of such methods.

Guideline development, as part of educational strategies, and the use of so-called 'toolboxes' also proved of significant use in fostering people-centered approaches to care. All of these systems and tools require adequate information technology or at the very least structured patient and family records held as databases or in a formal Registry, without which needs assessments, care planning, the evaluation of progress and clinical outcome measurement/description all become essentially impossible, severely limiting the possibility of developing people-centered approaches at the level of the population and person-centered care at the level of individuals. The WHO Report [13] recognises, from direct observation of the examples given and from separate experience, that attempts to utilise these principles and methods in isolation from effective leadership at national and local level and in the absence of what might be termed a 'positive policy environment' and the commitment of senior government officials through personal authority and influence or through agreed governmental policy, is essentially futile. Neither can people-centered approaches to care or those at the level of the individual patient be successfully fostered without adequate education of all relevant health workers and the Report [13] recognises the need for training reform as part of the development of people-centered health care. Here, the institution of continuing professional development programmes and the use of practice standards, credentialing and auditing for existing professionals is of very particular importance as is the need to consider the potential for introduction of peoplecentered care teaching into undergraduate clinical curricula for those in training.

Discussion

Taken both individually and especially together, these examples provide a compelling indication of the nature and scale of improvements in people and person-centered care that is possible in the particular circumstances in which the reported improvements were attempted and achieved: low and middle income countries. Nevertheless, the WHO Report [13] has the status of a narrative record of the oral presentations made at the Third Geneva Conference and this is at once its strength, but also its weakness. Indeed, while these stories of health care quality improvement driven by the person-centered philosophy are both highly encouraging and greatly inspiring, they are no substitute for a scientifically rigorous documentation, analysis and interpretation of the results from suitably designed and controlled studies.

This is not to criticise the progress reported. On the contrary, the WHO Report [13]itself, emphasises that there is a lack of consensus on how to measure progress towards people-centered care and an urgent need to define indicators with which to set targets, monitor progress and evaluate the effectiveness of the variety of interventions that can be used to facilitate the development of the people-centered approach. Indeed, the Report [13] is clear that from a methodological point of view, the current health services research and development base for the operationalisation of people and person-centered medicine in low and middle income countries is substantially incomplete. Review of the associated literature shows that a plurality of methods has been used and research conducted in different populations under highly varying circumstances. This, as is pointed out, makes comparative essentially studies impossible and generalisation development of hazardous. The standardised methodologies for testing people and person-centered interventions under controlled experimental conditions, with subsequent evaluation of the results obtained, is therefore, crucial – and urgent.

Clearly, these experimental conditions (and the prioritised needs of communities, regions and countries) will differ markedly between high, medium and low income countries and the Report [13] is concerned to emphasise the need to include the last two of these sociocultural and economic contexts in methodological thinking as soon as possible, especially given that the greatest volume of literature available so far has been generated from research conducted in high income environments. Certainly, if the methods employed by the five countries documented within the Report [13] can be tested more rigorously and their results examined for generalisability and sustainability in the longer term, then the vision of the WHO and the INPCM for the operationalisation and maintenance of people-centered care in developing countries will translate steadily into an achieved health benefit and a great public good.

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