The early roots of the concept of person-centred medicine can be found in the comprehensive notion of health and the personalized approaches to medical care discernible in both Eastern and Western ancient civilizations [1,2]. Other significant precedents include contemporary developments in clinical medicine and public health challenging an overemphasis on specific organs and disease and seeking to place the whole person at the centre of medicine [3].

The recent coordinated global effort towards person-centred medicine started with an inaugural Geneva Conference on Person-centred Medicine in May 2008. It involved the collaboration of major international medical and health organizations and a group of committed clinicians and scholars [4].

The Second Geneva Conference took place on 28 and 29 May 2009 under the auspices of the University of Geneva Medical School and the University Hospitals of Geneva organized by the World Medical Association (WMA), the World Organization of Family Doctors (Wonca) and the International Network for Person-centered Medicine (INPCM), in collaboration with the Council for International Organizations of Medical Sciences (CIOMS), the World Federation for Mental Health (WFMH), the World Federation of Neurology (WFN), the World Association for Sexual Health (WAS), the International Association of Medical Colleges (IOMC), the World Federation for Medical Education (WFME), the International Federation of Social Workers (IFSW), the International Council of Nurses (ICN), the European Federation of Associations of Families of People with Mental Illness (EUFAMI), the International Alliance of Patients’ Organizations (IAPO) and the Paul Tournier Association.

The Conference had as principal purposes to examine and discuss key concepts of person-centred medicine and practical approaches for its implementation, to elicit useful initiatives on person-centred medicine and to engage international medical and health organizations on the Conference’s theme.

The Conference Organizing Committee was composed of J.E. Mezzich (World Psychiatric Association President 2005–2008), J. Snaedal (World Medical Association President 2007–2008), C. van Weel (World Organization of Family Doctors President 2007–2010) and I. Heath (World Organization of Family Doctors Executive Committee Member at Large). The Conference Secretariat was based at the International Center for Mental Health, Mount Sinai School of Medicine, New York University.

Financial and in-kind support for the Conference was provided by the University of Geneva, the Paul Tournier Association of Geneva, Person-centered Medicine & Psychiatry Programs, Conference registration fees and the emerging International Network for Person-centred Medicine [5].

The Conference was opened by the Rector of the University of Geneva and the Vice-Dean of its Medical School, as well as by the members of the Conference Organizing Committee. All
remarked on the tradition that was being established engaging Geneva as encounter point for the development of person-centred medicine.

The first scientific session involved presentations of leaders and representatives of the International Alliance of Patients’ Organizations, the International Network for Person-centered Medicine, the World Health Organization, the World Medical Association, the World Organization of Family Doctors, the Council of International Organizations of Medical Sciences and the International Council of Nurses. The presentation of policy statements and relevant institutional programmes reflected the value ascribed by these organizations to person-centred medicine. The abstracts of the presentations made at this and the following sessions of the Second Geneva Conference have been posted at the INPCM website, http://www.personcenteredmedicine.org.

Eight special initiatives relevant to person-centred care were presented in the second session. The presentations were made by representatives of several major organizations collaborating in the Second Geneva Conference and other prominent work groups. The diverse experiences presented from a range of fields revealed substantive achievements and promising opportunities for a medicine of the person.

Concepts and meanings of person-centred medicine were the subject of the third session. They focused on the role and worth of the person in medicine, the cruciality of sense of identity, empathy and engagement for optimal clinical care, and the value and impact of life experiences for the development in each individual of personalized medicine and health.

The fourth session presented and discussed procedures for person-centred diagnosis. Particularly covered were the significance of multilevel explanations and diagnosis in medicine, the key features of a person-centred integrative diagnosis addressed to appraise whole health using standardized and narrative descriptions reflecting interactions among clinicians, patient and family, as well as the prospects for person-centred diagnosis in general medicine.

A panel on programmatic contributions for person-centred medicine in a fifth session offered an opportunity for the presentation of brief statements by representatives of 12 collaborating organizations and groups from across the world. They attested to the relevance of person-centred approaches to medicine for an ample range of medical, health and social institutions.

The sixth session, at the beginning of the second day of the Conference, discussed procedures for person-centred treatment and health promotion. These included general features of person-centred integrative care, the prospects for a person-centred medical home in the USA, and WHO perspectives on person-centred healthiness, social determinants and health promotion.

Person-centred medicine for children and older people was discussed in the Conference seventh session. Such vulnerable populations represent particular challenges and opportunities from scientific and ethical viewpoints. The uniqueness and developmental sensitivity of the child were highlighted. Also pointed out were the complexity of health conditions in older people and the imperative need to attend to their values and perspectives.

Training and research on person-centred medicine was the subject of the eighth session. Specific topics included the development of pertinent guidelines and curricula for person-centred clinical care, the assessment of an epistemologically based person-centred medicine at Ambrosiana University in Milan, training and research on communication for person-centred outcomes, and broad programmatic features and objectives of research on person-centred clinical care.

The ninth conference session reviewed person-centred health systems and policies. WHO’s new focus on persons for the development of more promising global health policies and systems, as affirmed by the latest World Health Assembly, was given pointed attention. Also discussed was the role of health informatics for the construction of personalized medicine and complex health care systems. Last but not least was a review of the role and documented value of the person for the conduction of health care, training and research.

The final tenth session presented a conference summary and outlined next steps. Among the general conclusions were (1) a commitment to the importance of person-centred medicine for the health of people, noting the participation of a vast array of important medical and health organizations, a wish to share and collaborate and an understanding of the importance of grasping opportunities in the field; (2) the growing availability of resources, including general concepts and procedures as well as teaching materials and research tools; and (3) the importance of fitting the above resources into health care systems and into particular health care encounters, with special attention to person-centredness as an intrinsic quality rather than as an additional commodity, and the value of comprehensiveness, continuity, and attention to context as crucial features of good clinical care.

Anticipated next steps included the following: (1) completion of a joint editorial to be published in an international journal; (2) preparation of a Second Geneva Conference Summary Report, (3) publication of a set of selected papers presented at the Second Geneva Conference; (4) collaboration with WHO on Person-centred Medicine topics related to the 2009 World Health Assembly Resolutions; (5) organization of scientific events relevant to person-centred medicine, such as a prospective New York Conference on Well-Being and Person in Medicine and Health; (6) planning a clearinghouse of Person-centred Medicine documents; (7) upgrading an internet platform to support archival, informational, communicational and programmatic needs; (8) organization of a Third Geneva Conference on Person-centred Medicine in early May 2010, prospectively focused on a team approach across specialties and disciplines; and (9) development of an International Network for Person-centered Medicine to stimulate the above activities and to organize initiatives on conceptual and ethical bases, diagnosis, clinical care, training, research, health systems and public policies.

Proposals for future conferences included building bridges to the various specialties in medicine, the participation of different patient groups and the inclusion of representatives of additional health disciplines. Emphasis was made on consolidating the ideas from the first two conferences, and to use that for further work to enhance person-centred medicine.

The Second Geneva Conference was distinctly perceived by its participants as a stimulating success in terms of food for thought and shared commitment to build a paradigmatic shift in medicine and health care. A Third Geneva Conference was widely
anticipated as the next landmark in this unfolding process with the emerging International Network for Person-centered Medicine as the collaborative and flexible structure to coordinate and move forward a vision and programmatic efforts.

In order to extend the impact of the Second Geneva Conference, a plan was arranged with the *Journal of Evaluation in Clinical Practice* to publish a selection of the papers presented at the Conference. The authors of this Introduction, members of the Board of the International Network for Person-centered Medicine, assumed editorial responsibility to work with the authors of the selected papers in upgrading them for publication. The papers are presented thematically ordered in terms of institutional and policy perspectives, clinical concepts and clinical practice. We hope they offer a valuable contribution to the process of building person-centred medicine.

References

Introduction

The first edition of the Geneva Conference on Person-centered Medicine (when nobody knew if there would be another one) was organized in May 2008 by the World Psychiatric Association (WPA) through its Institutional Program on Psychiatry for the Person (IPPP) in collaboration with the World Medical Association (WMA), the World Organization of Family Doctors (Wonca) and several other global medical and health institutions under the auspices and on the premises of the Geneva University Medical School. Its overall theme was the exploration of the conceptual bases of a medical and health paradigm that refocuses their priorities from disease to the whole person. The momentum generated by this first encounter of distinguished clinical scholars and representatives of top professional associations led to the immediate planning and organization of the Second Geneva Conference in May 2009. Its general theme involved the articulation of concepts and practice, in line with the well-thought-out interventional nature of medicine. Similar dynamics and the need to have a firm institutional base to organize in a collaborative manner future Geneva Conferences and the further development of the field led to the decision to establish the International Network for Person-centered Medicine (INPCM).

This paper briefly reviews the ancient and modern historical background of this new paradigm. It then summarizes the objectives and proceedings of the first two Geneva Conferences on Person-centered Medicine. Finally, it delineates the emergence of the INPCM out of the Geneva Conferences process, its first institutional steps and early outlook.

Historical background

The earliest roots of person-centred medicine can be found in ancient civilizations, both Eastern (such as Chinese and Indian Ayurvedic) [1] and Western (particularly ancient Greek) [2], which tended to conceptualize health broadly and holistically. In fact, the meaning of the term health in Sanskrit, the mother of all Indo-European languages, is totality. Also noticeable in medical traditions from those early civilizations is a personalized approach to health care still practised in those lands. All these notions found a house in the encompassing definition of health, a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity, inscribed in the constitution of the World Health Organization [3].

The development of medicine in modern times has shown impressive scientific advances on the understanding of illness and innovative diagnostic and therapeutic technology. At the same time, such development has been accompanied by a number of distortions in the priorities and ethos of medicine [4]. Medical attitudes and practices have become drastically focused on disease and specific organs. Growing super specialization has led to compartmentalization of knowledge and fragmentation of services. Medicine has become to a certain extent a product to be commercialized as commodities are. Consequently, communication
among health professionals and especially between these and patients and their families has become superficial and precarious, with subsequent neglect in the attention to the patients’ concerns, needs and values. Hyperbolic concern for disease has led to lack of interest on the positive aspects of health and on the patients’ assets. This has marginalized prevention and health promotion. The fulfillment of ethical aspirations, such as the promotion of personal autonomy, responsibility and dignity, has suffered. A rigid and scientific observance of evidence-based practice has led to neglect both of the person’s experience and subjectivity and of health actions that in addition to curing are aimed at alleviation and consoling [5].

Contemporary advances on the personalization of medicine

Endeavours to refocus medicine on the person of the patient, the clinician and the members of the community at large have been distinctly noted in the past century. Illustratively, Paul Tournier, a Swiss general practitioner, discovered the transformational value of critical interpersonal experiences and of attending to the whole person and the biological, psychological, social and spiritual aspects of health. He presented his vision on Medicine de la Personne [6] and 19 other books translated to over 20 languages. Around the same time, American psychologist Carl Rogers demonstrated the significance of open communication and of empowering for individuals to achieve their full potential [7] and proceeded to develop a person-centred approach to therapy, counselling and education.

During the second half of the 20th century, Frans Huygen in the Netherlands, Ian Mc Whinney in the UK and Canada, and Jack Medalie in the USA and Israel struggled with the limitations of modern medicine noted above and committed themselves to promote a broad and contextualized understanding of health with high concern for their patients’ well-being. They went on to develop a generalist medical specialty under the terms of general practice and family medicine [8,9], which has characteristically focused on patient-centred care.

Sustained efforts to establish a person-centred medicine programme on epistemological grounds and to build a corresponding medical school and clinical teaching method have been undertaken by Giuseppe Brera [10], rector of Ambrosiana University in Milan. Yrjo Alanen [11] in Finland privileged attention to the meaning of patients’ experiences and the importance of their needs, and creatively combined psychosocial and pharmacological therapies.

Illustrating responses from global medical and health organizations, the World Health Organization, which incorporated in its foundational constitution the above mentioned comprehensive definition of health, has recently started discussions to introduce in it the term dynamic, meaning interactive, to characterize the relationship among dimensions of well-being and to add a spirituality dimension. Furthermore, for the first time, WHO is placing person and the centre of healthcare and public health, as reflected on the resolutions of the World Health Organization’s 2009 World Health Assembly [12].

The WMA through its Declaration of Helsinki for Medical Research and the International Code of Medical Ethics [http://www.wma.net (press releases)] is emphasizing its concern for the whole person. Through the triad of caring, ethics and science, the WMA is re-affirming the enduring traditions of the medical profession [13]. Furthermore, the physicians’ obligation to respect human life rather than to extend it blindly has been cogently argued by former WMA president Jon Snaedal [14]. The Wonca has recorded its commitment to persons and community in its basic concepts and values – continuity of care for all health problems in all patients within a societal context (http://www.woncaeu.org).

The WPA revealed since its foundation in 1950 clear indications of interest on person-centred care through its aspirations for science and humanism [15]. That interest evolved to the point that in 2005 the WPA General Assembly established an Institutional Program on Psychiatry for the Person. This programme sought to promote a psychiatry of the person, for the person, by the person and with the person [16]. Among its signal conferences were those organized in London (October 2007) in collaboration with the UK Department of Health and in Paris (February 2008) in cooperation with the WPA French Member Societies. In addition to a number of journal papers, monographs have been prepared on the Conceptual Bases of Psychiatry for the Person [17] and on Psychiatric Diagnosis: Challenges and Prospects [18].

The organization and meaning of the Geneva Conferences on Person-centered Medicine

The first two editions of the Geneva Conference on Person-centered Medicine took place at the Geneva University Hospitals on 29–30 May 2008 and 28–29 May 2009. They represented both landmarks and flagships in a process of building an initiative on medicine for the person through the collaboration of major global medical and health organizations and a growing group of dedicated scholars and clinicians. The institutions formally involved in either or both Conferences included the WMA, the Wonca, the WPA IPPP, the Council for International Organizations of Medical Sciences, the World Federation for Mental Health, the World Federation of Neurology, the World Association for Sexual Health, the International Association of Medical Colleges, the World Federation for Medical Education, the International Federation of Social Workers, the International Council of Nurses, the European Federation of Associations of Families of People with Mental Illness, the International Alliance of Patients’ Organizations, the University of Geneva School of Medicine and the Paul Tournier Association. To coordinate these efforts and strengthen the development of the field emerged from the Geneva Conferences process the INPCM, which in fact became the core organizer of the Second Geneva Conference.

The First Geneva Conference on Person-centered Medicine was aimed at presenting and discussing the experience on person-centred principles and procedures gained through a Person-centred Psychiatry Program, exploring the conceptual bases of person-centred medicine, and engaging interactively major international medical and health organizations and scholars in the field. It included sessions on international organization perspectives on person-centred medicine, related special initiatives, conceptual bases of person-centred medicine, personal identity, experience and meaning in health, a review of Paul Tournier’s vision and contributions, person-centred health domains, clinical care organization, person-centred care in critical areas, and person-centred...
public health. The upgraded papers presented at the Conference have been published as a supplement of the International Journal of Integrated Care [19].

One year later, the Second Geneva Conference was aimed at probing further key concepts of person-centred medicine and reviewing a number of practical approaches for the implementation of this approach through a collaborative effort with an enlarged number of international health organizations. Through nine sessions, it covered institutional perspectives and activities on person-centred medicine, other relevant initiatives, concepts and meanings of person-centred medicine, procedures for diagnosis, treatment and health promotion in medicine for the person, person-centred medicine for children and older people, as well as training, research, health systems and policies on person-centred medicine [20].

Among the conclusions of the Second Geneva Conference were a wide commitment to the importance of person-centred medicine for the health of persons and populations, clarification of the availability of conceptual, educational and research tools, and the need to fit these into health encounters and systems, affirming person-centredness as an intrinsic quality rather than as an additional commodity. There was consensus on organizing a Third Geneva Conference where emphasis would be placed on building further bridges to the specialized sphere of medicine, other health professions and various patient groups. Among additional next steps are the organization of relevant scientific events such as a New York Conference on Well-Being and the Person, publication of a joint editorial in an international journal, preparing a monograph with the papers presented at the Second Geneva Conference, responding positively to requests from WHO for collaboration on people-centred care strategies adopted by the 2009 World Health Assembly, and further development of the INPCM to help move forward collaboratively an optimized vision for health care.

The emergence and construction of the International Network for Person-centered Medicine

The INPCM is a direct conceptual and organizational outcome of the first two Geneva Conferences. In turn, it has become the main organizer of ensuing Geneva Conferences in collaboration with a growing number of top medical and health institutions and an also growing community of international experts. As of May 2009 the INPCM has been incorporated in New York as a non-for-profit educational, research and advocacy organization aimed at developing opportunities for a fundamental re-examination of medicine and health care to refocus the field on genuinely person-centred care.

Discussions at the Geneva Conferences have led to the formulation of person-centred medicine as dedicated to the promotion of health as a state of physical, mental, social and spiritual well-being as well as to the reduction of disease, and founded on mutual respect for the dignity and responsibility of each individual person. To this effect, the INPCM seeks to articulate science and humanism in a balanced manner, engaging them at the service of the whole person. The purposes of the INPCM may be further summarized as promoting a medicine of the person (of the totality of the person’s health, including its ill and positive aspects), for the person (promoting the fulfillment of the person’s life project), by the person (with clinicians extending themselves as full human beings, well grounded on science and with high ethical aspirations) and with the person (working respectfully, in collaboration and in an empowering manner through a partnership of patient, family and clinicians). The person here is conceptualized in a fully contextualized manner, consistent with the words of philosopher Ortega y Gasset, I am I and my circumstance.

Among the key principles of person-centred care are the following: (1) a wide biological, psychological, socio-cultural and spiritual theoretical framework; (2) attending to both ill health and positive health; (3) person-centred research and education on the process and outcome of patient–family–clinician communication, diagnosis as shared understanding, and treatment, prevention and health promotion as shared commitments; (4) respect for the autonomy, responsibility and dignity of every person involved; and (5) promotion of partnerships at all levels [21].

Anticipated INPCM activities include the following: (1) organization of conferences and other scientific meetings promoting person-centred care in medicine at large and in its various specialties and related health fields; (2) preparation of person-centred clinical practice guidelines relevant to diagnosis, treatment, prevention, rehabilitation and health promotion; (3) preparation of educational programmes, including curricula, aimed at the training of health professionals on person-centred care; (4) conduction of studies and research projects to explore and validate person-centred care concepts and procedures; (5) preparation of publications, including an International Journal of Person Centered Medicine, to disseminate and advance the principles and practice of person-centred medicine; (6) development of advocacy forums and activities to extend and strengthen person-centred medicine with the participation of clinicians, patients and families, as well as members of the community at large; and (7) establishment of an Internet platform to support archival, informational, communicational and programmatic efforts on person-centred medicine.

Organizations and individuals participating actively in relevant programmatic activities, such as the Geneva Conferences, will be invited to join the INPCM. It will be organizationally developed and guided initially by a board of five or six persons with a clear track record of work on person-centred medicine and committed to the advancement of the fundamental purposes of the organization. Support for the INPCM and its activities is expected to come, as it has been for its initial steps, from academic institutions, professional societies, governmental organizations, foundations, person-centred medicine and psychiatry non-profit academic programme funds, and conference registration fees. Support from industry sources may be accepted provided it is transparent and unrestricted. Further information on the INPCM can be obtained by visiting http://www.personcenteredmedicine.org

Concluding remarks

The reformulation of the central mission of medicine, recognizing the person as its fundamental focus and not simply a carrier of disease, is informed by the wisdom from great ancient civilizations and recent developments in clinical medicine and public health. Inertia among professionals and strongly established special interests represent enormous challenges. However, the growing convergence in the perspectives of the most important global health institutions, from the WMA to the World Health Organization as
well of representatives of patients and families and dedicated academic groups and emerging conceptual and experimental research support such repriorizing. The Geneva Conferences and the INPCM represent major forums and players on this paradigmatic journey to cultivate the soul and science of medicine and health.

References

Abstract

Rationale, aims and objectives Most professional medical care is provided in the community, and this determines the importance of primary care for the health care system. As family doctors are involved in the care of different health problems over time to the same individual, the personal dimension is strong. This paper analyses the importance of person-centred medicine from the perspective of primary care and family medicine.

Methods The views and opinions of the leadership of the World Organization of Family Doctors, Wonca, provided the background material. Wonca brings together national colleges and academies of family medicine around the world.

Results The community, with its social, cultural and economic characteristics, is an important determinant of illness, health and disease. This shapes the personal relation between patient and family physician, with its basis of trust, and determines the effectiveness with which primary care functions. Continuity and integration of care are important person-centred ‘techniques’.

Conclusions As the effectiveness of primary care is a major factor for overall effective health care, it is important to come to a better understanding of how to address the personal context of care and the mechanisms through which this determines outcome of care.

Most people with most of their health problems can be found in the community, most of the time: the ‘ecology of medical care’ [1] stresses the importance of self-care and lay care, in dealing with society’s burden of illness. Professional health care is only involved in a minority of health problems people experience, depending their decision to actually contact a health care professional. And although many consider this [1], only about one in 10 actually do so [2]. And in most cases, this will be a doctor or other health care professional in the community they live in. This, health care in the community, is the domain of primary care and family medicine [3]. This paper explores the importance of person-centred medicine from the perspective of primary care and the professional role of family physicians.

Primary care function

The ‘ecology of health care’ model [1] illustrates the central position of primary care, and of family doctors, as the liaison between population – community and the health care system. People present whichever health problems they feel the need to see a doctor for, and this individual presentation is the start of the episode of professional care. The ‘ecology model’ underlines as well, that most episodes of professional care will take place in the community, within primary care itself, while about 10% will include the hospital setting and medical specialists [1,2].

The community base of primary care brings with it an involvement in that community, and a focus on the population that lives there [3]. This in turn brings with it an orientation on the prevailing social, cultural and economic characteristics of that community, which determine health. This established partnership with a defined population and community over time is the context in which family doctors and other primary care professionals work. This is the setting in which people find access for unselected health problems in the course of their personal medical history, to find the most appropriate response. As a consequence, primary care and family medicine are dominated by the personal context of the persons that make-up the community it serves. Family physicians are as a consequence responsible for the most important health needs in the community and see over time, a variety of health problems in the same individuals, without restrictions to body system, quality of life or severity [4].

Concepts, effectiveness of care and the person at the centre

Primary care, in other words, is oriented at people and populations, rather than at pre-defined diseases or interventions as stand-alone issues. The person-centred nature comes forward in a number of core concepts [3]: the role of the medical generalist, who is...
responsible for all health problems, in all stages, without pre-selection towards their nature, or specific patients’ groups; the orientation on the context of the person with the disease, in terms of the community, the family or household and with it social determinants of illness, health and disease. In this, primary care brings together the psycho-socio-physical domains of illness and health: it integrates different care concepts (integrated care) and structures it over time (continuity of care). In this, there is strong emphasis on the personal dimension: family physicians and other primary care professionals foster a personal relation of trust with their patients over time, and in this, care is centred at the person of the patient. These are the concepts that determine the effectiveness with which family physicians – and primary care at large – function.

Implications for health care systems

Effectiveness of primary care is a major factor in determining the overall performance of the health care system – the stronger primary care is, the better population health is achieved [5]. This should be set against grave concerns of the failure of health care, to contain the costs it causes and its failure to respond to rising social expectations of health care that is people-centred, fair, affordable and efficient. Primary health care’s emphasis on people, the person with the disease, and not just the successful treatment of a disease is a core element of its success [6] and from this stems the call to strengthen health care systems through primary care. The development of primary health care at the basis of the system of care, was therefore regarded by the World Health Organization (WHO) as the possibility to secure three vital societal imperatives: (i) improve population health; (ii) preserve the financial viability of the health care system; and (iii) restore the orientation of the person with the disease: – ‘people at the centre of health care’ [5]. This has placed person-centred medicine right at the middle of health care policy that WHO’s World Health Assembly did set out to be pursued, in 2009.

This has led the World Organization of Family Doctors, Wonca, to pursue that every family in the world should have access to a family doctor, a family physician for every community [7]. Yet, it is important to understand better the mechanisms behind this and unravel the paradox of why generalist health care with an emphasis on the person with the disease is more effective than treatment of diseases in isolation. At this moment, this is a black box [8] with the paradigms of person-centred care, integration, continuity of care over time and care in the context of the family and social environment as mere hypotheses.

Conclusions

Gaining more insight in person-centred medicine is essential to make it possible to further strengthen health care for people and populations. This way, health care can secure its moral obligation to provide care according to the principles of equality and equity: (i) all people are equal and equally entitled to the best care available; while (ii) focusing care towards those in greatest needs according to their individual and social context.

References

When people are sick they are a great deal less concerned about managerial considerations of productivity, health targets, cost-effectiveness and rational organization than about their own predicament. Each individual has his or her own way of experiencing and coping with health problems within their specific life circumstances [1]. Health workers have to be able to handle that diversity. For health workers at the interface between the population and the health services, the challenge is much more complicated than for a specialized referral service: managing a well-defined disease is a relatively straightforward technical challenge. Dealing with health problems, however, is complicated as people need to be understood holistically: their physical, emotional and social concerns, their past and their future, and the realities of the world in which they live. Failure to deal with the whole person in their specific familial and community contexts misses out on important aspects of health that do not immediately fit into disease categories.

People want to know that their health worker understands them, their suffering and the constraints they face. Unfortunately, many providers neglect this aspect of the therapeutic relation, particularly when they are dealing with disadvantaged groups. In many health services, responsiveness and person-centredness are treated as luxury goods to be handed out only to a selected few.

In practice, clinicians rarely address their patients’ concerns, beliefs and understanding of illness, and seldom share problem management options with them [11]. They limit themselves to simple technical prescriptions, ignoring the complex human dimensions that are critical to the appropriateness and effectiveness of the care they provide [12].

Thus, technical advice on lifestyle, treatment schedule or referral all too often neglects not only the constraints of the environment in which people live, but also their potential for self-help in dealing with a host of health problems ranging from diarrhoeal disease [13] to diabetes management [14]. Yet, neither the nurse in Niger’s rural health centre nor the general practitioner in Belgium can, for example, refer a patient to hospital without negotiating along with medical criteria, they have to take into account the patients’ values, the families’ values and their lifestyle and life perspective [17].
Few health providers have been trained for person-centred care. Lack of proper preparation is compounded by cross-cultural conflicts, social stratification, discrimination and stigma [16]. As a consequence, the considerable potential of people to contribute to their own health through lifestyle, behaviour and self-care, and by adapting professional advice optimally to their life circumstances is underutilized. The current payment systems and incentives in community health care delivery often work against establishing this type of dialogue [18]. Conflicts of interest between provider and patient, particularly in unregulated commercial settings, are a major disincentive to person-centred care. Commercial providers may be more courteous and client-friendly than in the average health centre, but this is no substitute for person-centredness.

References
The traditional picture of a government department is perhaps of everyone avoiding headaches! It is thus particularly exciting that the UK government’s Department of Health has backed a whole series of initiatives aimed at increasing what they are calling the ‘personalization’ of care. Translated, this means nothing more nor less than a government-backed policy for ‘person-centred medicine’.

This paper describes how bringing values-based and evidence-based approaches together is contributing to the development of person-centred medicine in the context of these Department of Health initiatives. The paper covers:

1 What values-based practice is.
2 The relationship between values-based practice and evidence-based practice.
3 Some recent applications of values-based practice in mental health that are being developed through the Department of Health in London.
4 How values-based practice is now being extended from mental health into other areas of medicine.

**What is values-based practice?**

The starting point for values-based practice is the way in which increasingly complex and often conflicting values are becoming ever more visible in health care. This is evident enough in ethics, of course, with ethical dilemmas in all areas of medicine. But values are also increasingly evident in such areas as health economic decisions, in the development of guidelines and in many other areas.

A number of disciplines offer resources for working with complex and conflicting values. The most widely recognized of these disciplines is ethics. But other important disciplines include the social sciences and the medical humanities, and also more quantitative disciplines such as decision analysis [1] and health economics [2].

Values-based practice, which is derived from philosophical value theory [3], adds to the growing ‘toolkit’ for working with values a new and primarily skills-based approach to balanced...
Values-based and evidence-based medicine

K.W.M. (Bill) Fulford

It is important to emphasize that word ‘skills’. The effectiveness of values-based practice in day-to-day clinical care depends very much on the fact that it builds on learnable clinical skills.

The relationship between values-based practice and evidence-based practice

There is a close relationship between values-based practice and evidence-based practice. This close relationship is evident at a number of levels. First, values-based practice and evidence-based practice are both about process: they give us tools for answering questions rather than answers as such. Thus, evidence-based practice gives us practical tools for working more effectively with complex and conflicting evidence. Correspondingly, values-based practice gives us practical tools for working more effectively with complex and conflicting values.

But the relationship between evidence-based practice and values-based practice goes much deeper. This deeper relationship is illustrated by the definition of evidence-based practice given by one of the founders of evidence-based practice [4]. Evidence-based medicine is often thought of as being mainly about best research evidence, and of course best research evidence certainly is at the heart of evidence-based medicine. But properly understood, Sackett argues (p. 1), evidence-based medicine encompasses a good deal more. Again, it is about best research evidence, but it is also about clinical experience and, crucially, patients’ values.

Sackett, furthermore, goes on to define values in a way that is directly equivalent to how they are understood in values-based practice. ‘By patient values’, he says, ‘we mean the unique preferences, concerns and expectations each patient brings to a clinical encounter and which must be integrated into clinical decisions if they are to serve the patient’ (p. 1) [4].

Practical applications of values-based practice

Values-based practice is being applied in a number of initiatives through the Department of Health in London. These initiatives fall into two main areas:
• training
• policy

Training

A training manual [5], developed in a partnership between a major mental health non-governmental organization in London, The Sainsbury Centre for Mental Health and Warwick Medical School, was launched by the Minister in the Department of Health at the time, Rosie Winterton. It is this manual that has subsequently become the basis for a series of Department of Health initiatives in values-based practice.

One example of these initiatives is a programme called ‘The Ten Essential Shared Capabilities’ or ‘10 ESCs’ [6]. This set out the generic skills (i.e. the essential shared capabilities) required to support anyone working in mental health. The diagram in Fig. 1 below, which was published in the 10 ESCs’ document, makes explicit the way in which the 10 ESCs build on the twin foundations of values-based practice working alongside and in partnership with evidence-based practice.

Policy

A further application of values-based practice has been in the training materials that have been developed by the Department of Health to support implementation of a revised Mental Health Act [7]. This Act was one of the corner stones of the government’s mental health policy covering the use of compulsory treatment. Such treatment by its very nature involves conflicting values (the patient wants not to be treated, everyone else wants them to be treated) and values-based practice, building on a set of Guiding Principles in the Code of Practice supporting the Act [8], was the basis of training materials aimed at securing balanced use of the provisions of the Act in practice (Care Services Improvement Partnership and the National Institute for Mental Health in England) [9,10].

A second example of the policy applications of values-based practice has been to assessment in mental health, as set out in a guidance document, called the ‘3 Keys to a Shared Approach in Mental Health Assessment’ [11]. The ‘3 Keys’ illustrates particularly clearly the importance of partnership as a feature of values-based practice. The whole document was a co-production between myself, as the Department of Health Lead for Values-Based Practice, and also a clinician and researcher, working closely with Laurie Bryant, as the Department Lead for Patients, and Lu Duhig, as the Lead for Carers and Families.

Recently, there has been a whole series of new Department of Health policies aimed at increasing the extent to which services are responsive to the individual needs of patients and their families. These policies cover such areas as care planning (the Care Programme Approach), delivering race equality and social inclusion. But the important point is the overall theme of increasing person-centred medicine.
From mental health into the rest of medicine

Building on these initiatives in mental health, the challenge now is to develop similar values-based approaches across medicine more widely.

I will not have time to go into this in detail. But, encouragingly, we have ‘policy headroom’ for this, at least in the UK, in the form of a recently published Department of Health report that has been adopted as the basis of health policy for the coming few years [12]. This report, which was produced under the leadership of a surgeon, Lord Darzi, is all about person-centred medicine.

There will be many challenges here! We need to develop new educational methods and new structural and policy supports, and we need to find ways of integrating values-based processes into clinical trials methodologies and into clinical guideline production. A key challenge for the latter will be the development of effective literature search tools.

Warwick Medical School, which as noted earlier spearheaded the development of training methods for values-based practice in mental health, has again taken the lead here with a number of teaching and other initiatives. These initiatives include the development of a manual (by one of my postgraduate students, Mila Petrova) that draws together findings on how to search for health-related values in electronic databases. We have also recently signed a contract with Cambridge University Press for a book series on values-based medicine.

Conclusions

Values-based practice is a new skills-based approach to working with complex and conflicting values that, working in partnership with evidence-based practice, has been successfully rolled out through a number of training and policy initiatives in mental health through the UK government’s Department of Health. The development of similar values-based and evidence-based approaches across health care as a whole could make an important contribution to the development of a medicine for the 21st century that is not only fully science-based but also genuinely person-centred.

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11 The National Institute for Mental Health in England (NIMHE) and the Care Services Improvement Partnership (2008) 3 Keys to A Shared Approach in Mental Health Assessment. London: Department of Health.
Abstract

Rationale European Federation of Associations of Families of People with Mental Illness is working towards the goal of shifting the emphasis of care for people with mental illness from the treatment of the symptoms to a more holistic approach of treating the whole person – in other words ‘person-centred care’. It is also working with the Geneva conference on person-centred medicine and various interested groupings and organizations to ensure that the role of the family is fully recognized and supported.

Method By engaging primarily with the medical community in bringing to fruition certain initiatives which European Federation of Associations of Families of People with Mental Illness considers as important to the success of person-centred care.

Results To date, no formal reviews have taken place and feedback from the initiatives has been informal and anecdotal.

Conclusion Early reports from the various initiatives are positive. But they also indicate that there is still much work to be done in order for the concept to become a reality across the majority of European countries.

Keywords
empowerment, EUFAMI, family, partnership, prospect, training, trialogue

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At the outset, I would like to introduce our organization to those who may not be familiar with it. EUFAMI is the European Federation of Associations of Families of People with Mental Illness (http://www.eufami.org). It is the representative body for family-run voluntary organizations across Europe, which promotes the interests and well-being of all people affected by severe mental illness. It was founded in 1992 and has 48 member associations from 28 European countries.

European Federation of Associations of Families of People with Mental Illness campaigns on behalf of many millions of people across Europe affected by severe mental illness. It aims to represent their concerns in the European institutions such as the European Union Commission and the European Parliament, the World Health Organization and other European and international forums and bodies, including many professional medical bodies, such as the World Psychiatric Association as just one example.

European Federation of Associations of Families of People with Mental Illness believes that families/carers must be acknowledged as equal partners alongside professionals supporting patients and recognizes that families/carers need support in their own right and have many unmet support needs that must be respected and recognized. Additionally, EUFAMI believes that all patients with mental illness have the right to appropriate social care and health care services and that all people affected by severe mental illness have the right to share in the opportunities, responsibilities and fulfilment of everyday life.

The Federation works with partners and stakeholders in the public and private sectors that share its concerns and beliefs and together seeks solutions for mental health issues, furthering better quality of care and welfare for people with a mental illness and support for their family and friends.

In order to fully consider ‘person-centred’ care, it is essential that a common understanding be first established and that certain central characteristics are identified – for instance, all parties must be involved, true partnership is essential and that there is a culture of mutual respect and that services are integrated.

It should also encompass principles as
• taking into account the patient’s preferences, needs and environment;
• adopting an individual approach;
• developing a partnership with patients and their families;
• ensuring continuity of care, which must involve engaging the family;
• treating the patient as a person and not merely treating the symptoms.

Families can become empowered through ‘person-centred’ care and a sense of commitment and a feeling of being valued can be achieved. Family involvement can help to reduce stress (by listening and giving space to ‘chill out’ or ‘let steam off’), help to establish a regular routine and encourage adherence to the care plan and to medication.

The role which families play is a most important one when one takes into consideration what family members do – such as
providing help when necessary while respecting the wish and need of the patients to help themselves. On many occasions, they are the only social contact for the people with a mental illness; family members can also recognize the healthy aspects and their skills in addition to seeing the illness. Families can still maintain the trust and confidence of the patient, even if his or her attitude is unpleasant.

Their contribution must be acknowledged appropriately and they should have the right and opportunity to state their needs and to define the role they are willing and able to play. In respect to support for the family, quality information to help understand the illness and education to help develop one’s coping skills is urgently required.

I will refer to three examples of initiatives in which EUFAMI members are participating in their quest to have the focus shifted more on the patient. These include:

**Empowerment and information**

A few years ago, EUFAMI along with a number of its member associations embarked on a unique project programme to help families become self-empowered. This resulted in the development of PROSPECT – a very unique peer-to-peer training method which would be delivered by family members.

Drawing on best practice within the PROSPECT partnership and EUFAMI’s network, the aim of the PROSPECT training programme is to support recovery from mental illness and promote inclusion in the community for people with self-experience of mental illness (patients), their family and their carers. It trains and educates participants to develop their skills and competencies to create new opportunities for social integration and employment. In addition, it seeks to sensitize social and health professionals to new approaches.

PROSPECT training programmes have a number of flexible, integrated modules which include modules for professionals and patients, in addition to the modules for family members. Each module is led by a facilitator drawn from the target group; for example, a family member facilitates the modules for families. There is also a common module which embraces all three groups. PROSPECT has now been successfully used in over 14 European countries and continues to primarily help our members in their mission to promote the objective of total care, which involves all parties.

**Trialogue**

This second initiative, known as Trialogue, is addressing issues around communication. Traditionally, interactions and communication occur only between the patient and the professional or between the patient and his or her carer. However, this results in a communication gap between the health professional and family members. This gap can only be bridged by speaking with one voice, in a spirit of cooperation. The Trialogue model – a three-way discussion between service users, professionals and family members – is being used in a number of countries in a flexible way to address specific issues for individual patients and their family carers. It is the strong belief of EUFAMI that the Trialogue model does work and is the solution to many issues around the communication gap. EUFAMI can provide examples of strength through working together at both individual and organizational levels.

**A new approach to professional training**

With regard to current training and training methods for psychiatry, EUFAMI contends that a major seed change is required to ensure that the emphasis is placed more on the patient rather than on the illness and second that ‘family training’ is recognized as part of the official training curriculum.

Relatives have gained a great deal of experience and have much to teach the medical community. Their expertise should be acknowledged and valued. Families should be involved in education and training of medical staff working in mental health services. Involvement of carers in mental health training is a beneficial development for patients and professionals, but one that requires further work.

We are aware that family members are becoming involved, albeit on an informal basis, with professional training in a number of countries, such as the UK and Germany. From the limited amount of feedback we have received, it is becoming clear that mental health professionals are acquiring a more positive attitude towards families; they use less jargon and are becoming more optimistic about patients’ recovery. Families and carers, on the other hand, feel more empowered, have a better relationship with mental health professionals and enjoy far more personal satisfaction and improved quality of life. It is clear that attitudes will dramatically change and that everyone will benefit – especially the person with the mental illness, as the barriers begin to come down.

EUFAMI contends that this type of initiative should be implemented on a wider geographic spread and on a formal basis.

New modules need to be introduced to cover human aspects related to the patient and family. In the long run, the participation of all interested parties in the care team will evolve and will result in a better and easier life for all concerned – the patient will feel more involved and take ownership; the medical profession will feel more relaxed and life will be easier as there will be more dialogue; the family member will feel valued and a reduction in isolation.

A change in the current care environment is badly needed in order to move from the long-term hospital model to a more acceptable care model centred within the community environment. The new module should include psychiatric departments within regional hospitals in place of the large psychiatric clinics that currently operate. A more holistic model is needed which should address all aspects of a patient’s health; empowerment and recovery brings new responsibilities to all parties and the roles of clinicians, patients, carers require updating.

European Federation of Associations of Families of People with Mental Illness is leading the campaign to ensure that the voice of families is recognized and is listened to so that the vast knowledge base and experience which families have built up from years of caring and living with mental illness on a ‘round-the-clock’ basis is available for sharing by all of the care team. This is a prime reason why families are officially as an integral part of the primary care team.

It is very clear that the manner in which families and medical professionals approach life and issues is very different – families tend to be impatient and thus approach issues in a very pragmatic
way, whereas professionals view an issue from evidence-based perspective. EUFAMI appreciates the difference and recognizes an ever-increasing body of evidence based on many initiatives and greater awareness in this area. 

Ultimately, we all want good services, support, information, advice, training and advocacy and an end to stigma and discrimination. This can only be achieved by putting the patient at the centre of the system.
The person in health care policy development

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Abstract
Objective The objective of this article is to explore the rationale for involvement of persons in health care policy in western countries, and to examine evidence of the difference public involvement can make.

Methods The information is drawn from research and reports on changes in health care policy towards greater democratization of decision making.

Conclusions Strong reasons have been put forward for wider public involvement in health care policy, and some evidence is now available that involvement is popular with stakeholders and can improve services, though it is a complex intervention needing complex strategies of evaluation.

Why involve the person in health care policy?

Historical and sociological reasons
Health care policy has been seen as problematic by many members of society; although during the first half of the 20th century patients were grateful (or were expected to be grateful) for the care they received, and rarely formed a lobby for change. Patients of psychiatry were particularly disempowered by their legal status as well as their actual problems and the stigma ascribed to their condition.

Health care in most western countries is characterized by inequality in health according to social class [1]. There is also usually an allocation of resources that is biased towards the wealthier classes, which Tudor Hart [2] termed the ‘inverse care law’, that is, that those people in the worst health receive the least services.

In addition, the allocation of resources has been concentrated on hospitals, despite the fact that most illness is treated by local doctors.

Health care policy therefore came under criticism in the latter part of the 20th century from people who need services, their friends and relatives, as well as from many health care workers and researchers.

The tendency for health care political lobbies to be formed was fed by social change in this period. The crisis in industrial culture led to new social movements [3] no longer based primarily on economic concerns such as wages and working conditions. People organized around identity, ecology, peace and eventually around health issues. Disabled people, service users, patients and carers formed associations to press for more rights, choice and empowerment in health policy.

Philosophical and ethical reasons
The philosophy of science as it applies to medicine is a crucial element in health care policy changes. As 19th and 20th centuries medicine became increasingly reliant on technology, so an increasing number of doctors felt themselves disempowered in their medical decision making. Science was expected to answer all the questions, yet laboratory tests are not always sufficiently exact; and progress measured by numbers and graphs does not answer quality questions about illness and wellness.

Evidence-based medicine as advocated in the 21st century is still based on a positivist belief that all questions can be referred to an exact science, or at least to the best available accumulated scientific and technical knowledge, rather than to the doctor’s own knowledge and experience or a combination of observation, examination, history taking and the patient’s own perspectives on what is wrong.

Advocates of history-taking argue, basically, that while instruments and the senses may reveal crucial facts about the causes of disease, only the patient can reveal how the illness affects him’ [4].

In the late 20th century there were a growing number of critics of overdependence on scientific medicine. Some used a philosophical/ethical critique of the direction of biomedical
science, arguing for a more negotiated social perspective on health care needs. These included philosophers of science such as Capra [5], who argued:

Medical problems are reduced to molecular phenomena with the aim of finding a mechanism that is central to the problem. Once this mechanism is understood, it is counteracted by a drug that is often isolated from another organic process whose ‘active principle’ it is said to represent. By reducing biological functions to molecular mechanisms and active principles in this way, biomedical researchers necessarily limit themselves to partial aspects of the phenomena they study . . . all aspects that go beyond this view are considered irrelevant, as far as the disorders are concerned, and are listed as ‘side effects’ in the case of the remedies. pp. 129–130

Universities participated keenly in these debates about philosophy and ethics of medicine, and the work of academics was eventually reflected in the arena of public involvement in health care policy. Many consumers of health care began to argue for a more qualitative and negotiated approach to health care. Even in the case of clearly measurable diseases such as cancer this approach was seen as important to coexist with continued biological research. In more contested areas such as mental health the arguments for qualitative approaches have been even stronger.

**Decision-making theory**

Social and philosophical debates about the problems of technologically dominated decision making were one form of influence on politicians in the later part of the 20th century causing them to seek greater public involvement in health care and social policy. Decision theory is often concerned with how to make decisions that are difficult because of their complexity, or because the outcomes of courses of action cannot be accurately predicted.

In the health care area, decisions are often complex and are often based on information that is fundamentally ambiguous and multifaceted:

Uncertainty can be resolved in principle by more cognitive advances . . . [but] ambiguity only by discourse. Discursive procedures include legal deliberations as well as novel participatory approaches. In addition, discursive methods of planning and conflict resolution can be used. If ambiguities are associated with a risk problem, it is not enough to demonstrate that risk regulators are open to public concerns and address the issues that many people wish them to take care of. The process of risk evaluation itself needs to be open to public input and new forms of deliberation. [6]

Thus, governments have concluded that techniques such as Delphi, qualitative surveys and stakeholder involvement can lead to wiser, more humane, or at least, more firmly grounded, shared and acceptable public health care policies.

**Scientific research basis for power-sharing in health**

Some research suggests that empowerment of patients and communities leads in itself to better health outcomes and reduced hospital costs [7]. Rappaport [8] defined empowerment as individual determination over one’s own life and democratic participation in the life of one’s community, along with a psychological sense of personal control and an interest in social, political and legal participation. He argued that moving from ‘helpee to helper’ can be empowering. He suggests that organizations with an ideology of empowerment are more successful at finding and developing resources than those with traditional power structures, as ‘empowerment is not a scarce resource that gets used up’.

Mental health service users have further defined empowerment as a concept including self-esteem, power, activism, optimism and righteous anger [9].

The pharmaceutical industry [10] is aware that empowered patients can influence health care outcomes in terms of ‘access to drugs, reimbursement policies, approval of new drugs, clinical trial recruitment, patient compliance and prescription rates’. However, they are also concerned that empowerment may lead to a reduction in drug prices and negative publicity for the pharmaceutical industry, and advocate effort in harnessing (controlling and directing) patient power through working with patient advocacy groups, where legal restrictions allow.

A WHO (2006) report demonstrates that empowering initiatives can lead to valued health outcomes and that empowerment is a viable public health strategy, although they argue that empowerment is a complex strategy that is difficult to evaluate. [11]

**Benefits of genuine public involvement in health care**

An article in the British Medical Journal [12] states that paternalism in health care is outdated:

Benign and well intentioned [paternalism] may be, but it has the effect of creating and maintaining an unhealthy dependency which is out of step with other currents in society. Assumptions that doctor (or nurse) knows best, making decisions on behalf of patients without involving them and feeling threatened when patients have access to alternative sources of medical information – these signs of paternalism should have no place in modern health care [12]

The benefits and potential benefits of power-sharing with patients are driving current research on patient participation in health care decisions. In Quebec [13] a literature review and action research project is seeking to increase participation in Health Technology Assessment (HTA) processes.

The researchers say:

Given the actual state of evidence, integrating patient perspective in HTA activities has the potential to improve the quality of healthcare services. This study provides an opportunity to bridge the gap between HTA producers and its ultimate end-user: the patient. It will provide guidance to support local HTA units in Quebec and elsewhere in their decisions regarding patient participation [13].

**Examples of changes because of public involvement in health care**

One example of the benefits of power-sharing between professional health care workers and service users will serve as typical. A study of involvement of patients in diabetes research [14] found:

Users contribute by changing the researchers’ mind-sets, thus increasing their confidence in the relevance of this research. Proposals are, from the very beginning, drafted with the users...
in mind. Researchers also view their interaction with the group as essential for conducting research that is feasible in practice. They found that the impact stems from the continuing interaction between researchers and users, and the general ethos of learning from each other in an on-going process.

Randomized controlled trials looking specifically at the impact of consumer involvement in health care policy are so far inconclusive according to a recent Cochrane review [15], finding only that involving consumers can produce more relevant, readable and understandable patient information material, which can improve knowledge.

However, the generally accepted view is that shared decision making can be effective, and is popular with patients, service users, families and carers as well as medical and health care workers in all fields. In the longer term it could lead to more responsible citizenship where people make better health choices and learn to care for themselves and those around them.

References
Empathy, identity and engagement in person-centred medicine: the sociocultural context

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Abstract

Aims This paper considers in outline the complexity of the empathic process from subjective, philosophical and psychological perspectives, and suggests that compassionate empathy is a core requirement of a person-centred approach to health care delivery. Empathy is facilitated by secure attachments in infancy (intersubjectivity) and a subsequent firm sense of self and personal identity. Empathic understanding is enhanced by the medical humanities, but the neglect of musical appreciation in this regard is surprising.

Conclusions The biopsychosocial model is reviewed, and a body-mind-spirit paradigm is proposed as a more optimal framework for health care delivery in a multicultural society.

Empathy

Rogers regarded accurate empathy, genuineness and non-possessive warmth as key components of humanistic counselling. It is suggested in this paper that empathic understanding is also central to the provision of all person-centred, relationship-based health care.

The psychological and philosophical understanding as to how empathic ‘judgement’ about another person’s subjective world is made, include psychoanalytic concepts of transference and projective identification [3], as well as ‘Simulation theory’ [4] and the ‘Theory–Theory’ of cognitive psychology [5], whereby knowledge of another’s mind can only be theoretical and not experiential. How empathic capacity is acquired whether in infancy from the experience of intersubjectivity [6] or with a sensitive caregiver or later through sensitivity training or the teaching of medical humanities, are key research questions in this field.

Karl Jaspers [7], psychiatrist and philosopher, gave particular emphasis to the role of fellow feeling and hence to the simulation of moods and feeling states, on the basis of which
intentionality and behaviour of the other might be predicted. Likewise, he emphasized the value of ‘understanding’ (Verstehen) of another’s experience, in contrast with explanation, and showed that subjectivity can only be understood through the process of empathizing:

Subjective symptoms cannot be perceived by the sense organs, but have to be grasped by transferring oneself, so to say, into the other individual’s psyche; that is by empathy. They can only become an inner reality for the observer by his participating in the other person’s experiences, not by intellectual effort. [8]

This capacity for accurate and compassionate empathy is thus partly contingent on the subjective experiences of the observer – the extent to which he or she has experienced the emotions being imputed to the other. The doctor, for example, who has not grieved cannot fully simulate (empathize with) a grieving patient [9] – although during the process of therapy the practitioner will learn more about the range of feelings and behaviours that may characterize this state of mind.

The accuracy of this empathic process with patients is nevertheless often difficult for health professionals to attain, especially when working with patients from communities that are themselves undergoing rapid transition or when the way in which health care is delivered is itself in transition. Any lack of shared assumptions or values can result in demoralization and depersonalization of both the health care professional and the patient [10].

It is to assist with anticipating and overcoming these difficulties of empathic understanding that the teaching of ‘medical humanities’ in medical schools is commonly justified [11]. The appreciation of poetry, of the visual arts and of drama can each enhance the understanding of the human condition and sensitize doctors to their own emotional responses. It has been suggested by Green [12], for example, that an empathic process establishes the emotional response to a painting and the ‘relationship’ with its sentiment and the creativity of the artist.

Likewise, the response of the listener and the performer to a composer’s music is also an empathic process, which requires the mirroring of emotional expression and the activity of complex neuronal circuits involving the auditory pathways, the amygdala and the reverberating circuits involved with emotion-laden memories [13]. This teaching of music appreciation is however rarely included in medical humanities curricula, even in intercalated Bachelor programmes [14], and there is no clear explanation for this neglect at the present time. Interestingly, the musicologist Anthony Hopkins [15] has aptly pointed out that, unlike a poem or a painting, music is an art form that is constantly renewed and revitalized as it is performed and cannot so readily be put in a cupboard or taken home. These are practical considerations that the teacher of medical humanities would have to take into account, as well as the possibility that the medical student may have had little exposure to musical appreciation before – or may be tone deaf.

Nevertheless, developing the capacity for compassionate empathy, whether through the teaching of the medical humanities or from supervision or personal experience, is necessary for optimal communication with the patient and for enabling the patient to feel understood and ‘listened to’ [16].

Identity and personhood

‘Identity’ is a term used in the Social Sciences to describe a sense of self as a separate entity. According to Erikson’s staged theory of human development [17], this sense of personhood is achieved by the inculcation of Basic Trust in the growing infant. The ability to relate confidently to others arises out of the early experience of Secure Attachment to the caregiver in infancy [18]. It is therefore contingent on the ability of the caregiver to have sufficient empathic capacity to introduce the infant to the external world, and to facilitate the mentalizing processes necessary for human brain development. Thus, empathy is not just entering and sharing the feelings of the other, but it is also the capacity to look out with the other and to see the world as he/she sees it [19].

Thus, for a person-centred medicine, the doctor (or other health professional) will benefit by having a firm enough sense of his/her own professional, cultural and social identity, which will facilitate the therapeutic relationships with service users who seek help. For some professionals, an anchoring in a religious faith tradition or another existential worldview is an advantage, especially when working in high-stress specialties, such as Forensic Psychotherapy [20], Intensive or Palliative Care [21], when the demands made on the person are continuous and at times daunting.

Gilbert [22] has discussed further these existential, social, psychological and theological components of the Personal and Social Self and illustrates them in his figure of a diamond of ‘Self and Others’.

The South African psychiatrist and philosopher van Staden [23] regards psychiatry as a discipline primarily concerned with patients as persons. Meaningful philosophical constructs (such as brain or body) are ‘extricates’ from persons – and not vice versa. The whole patient, rather than a mind or a body, is therefore logically and historically at the centre of psychiatric practice; the person is regarded as being primary in relation to its ‘contributory subjects’, such as biology, psychology and sociology.

Drawing on the work of Husserl and Merlau-Ponty, Eric Matthews [24] has summarized his reasons for replacing Cartesian dualism with Merlau-Ponty’s conception of human beings as body-subjects in the following way:

The mind then is not thought of, as in Dualism, as a thing, which constitutes one part of a human being. Rather human beings are thought of as wholes, which exist in the world, and whose bodies (including their brains) are experienced as their means of existing in the world.

Person-centred medicine and a medicine of the person

Person-centred approaches to health care are commonly advocated by User and Carer groups across the world, and promoted in policy papers, such as ‘Shared Decision Making’ [25], which emphasized the partnership between doctor and patient, and the Kings Fund report [26], ‘Seeing the person in the patient’.

Thus, patient-centred medicine or medicine of the person [27,28] has broad policy as well as clinical components, which include regarding the patient as person, biopsychosocial perspectives, sharing power and responsibility, therapeutic alliance and the doctor as person [29].
The biopsychosocial model

The biopsychosocial model [30] of George Engel has exerted a wide influence on medical practice in general, and was a bridge between the schools of Psychoanalysis and Biological Psychiatry in the USA in the 1970s. It was conceived as a scientific, rather than a values, framework that would hold together the biological and psychological sciences. The model has nevertheless provided a framework for the emerging desire for greater multi-professional collaboration and for increased consideration of the perspectives of service users. It also provided an integrative focus for those who recognized the conceptual limitations of a medical practice based on biomedicine alone – even when this was the dominant explanatory model of the time. George Engel described how psychiatrists were saying at that time when they had ‘strayed from medicine and the medical model – so please take us back’. But he understood that medicine itself was changing, and that a narrow biomedical model was no longer adequate for the scientific and social responsibilities of medicine as a whole and psychiatry in particular.

Engel also recognized the importance of the historical split between mind and body in Western medicine, with the church and social institutions being responsible for the mind, and the doctor for the body. As a Consultation/Liaison psychiatrist, he noted that considering the behavioural and social aspects of a patient with diabetes was comparable to the holistic management of a patient with schizophrenia. Thus, the requirements of any new model at that time would include the consideration of the disease/illness dichotomy and the understanding of the ‘meaning’ of a patient’s narrative.

Using anthropological references, the psychological and social factors were commonly determinants of a patient with a biochemical abnormality becoming ‘sick’. Engel aptly noted that the behaviour of the doctor and the relationship between doctor and patient would both influence therapeutic outcome – for better or worse. It was in this context that he put forward his biopsychosocial model, which was supported by General Systems Theory.

This model was however not described in greater detail, and George Engel did not refer to the conceptual and philosophical dilemmas at the brain/mind interface, nor did he suggest operational measures necessary to determine whether or not the model had been implemented. There was no indication as to how the model worked, or of any evidence that it worked. It remained unclear whether it was intended as an explanatory model of disease or an optimal approach to medical care.

The biopsychosocial model has encouraged a constructive eclecticism, but it has not provided a rigorous scientific or values-based framework for considering the conceptual issues of the brain/mind interface, or the basis for a values-based integrative approach to health care. One commentator [31] suggested that a more optimal model for the understanding of Disorder would be to re-establish a pluralistic ‘method based psychiatry’, which did not merge scientific disciplines but recognized that any necessary reductionism of research method could later be reintegrated into a more holistic understanding. Other writers [32] have noted the lack of the spiritual/religious dimension in the model and have suggested that a biosocial/psychospiritual approach for a relationship-based health care could more readily incorporate this existential perspective.

Body-mind-spirit paradigm

Considering the changes in the philosophy of science, and in particular the increased understanding of Tacit knowledge [33] and of the need for existential meaning making [34] in secular society, a body-mind-spirit paradigm may be a more useful integrative framework for contemporary health care provision. This interlocking whole person system would include, for example, ‘spirit’ in the sense of meaning and purpose, as well as the ‘intentionality’ of the body. This paradigm, which is derived fundamentally from the full understanding of the personhood of the individual in relationship with others, can not conceptually be taken apart without violating the understanding of the whole person.

Conclusion

This paper has outlined the impact of current sociocultural changes on the individual and on the presentation of distress. It is suggested that these upheavals affect internal medicine, family practice and psychiatry equally. Optimal medical practice, it is suggested, is a relationship-based medicine of the person, which incorporates meaning and purpose (spirit) as well as science and psychology, and so is truly integrative.

This approach is derived from the ‘person’, with brain and mind as ‘extricates’. Relationships between health professionals and patients are ‘compassionate’ when they are influenced by empathy and altruism. It is suggested that these virtues and values can be enhanced by the teaching of the Medical Humanities (including musical appreciation), by increasing the sensitivity to personal narratives and to greater understanding of values-based approach. It is suggested that a body-mind-spirit paradigm, which includes meaning and purpose as well as contemporary understandings of spirituality, is a useful framework for considering the complexity of person-centred care at times of marked existential uncertainty.

References


Outlining the bases of person-centred integrative diagnosis

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Keywords
diagnosis, diagnostic models, person-centred

Abstract

Rational and aims As diagnosis is a critical first step for clinical care, it was early recognized that an appropriate diagnostic model was necessary as informational basis for person-centred clinical care.

Methods The design of a person-centred integrative diagnosis model was based on literature reviews and work meetings in London, Paris, Geneva, Preston, UK and Uppsala, Sweden over the past 2 years.

Results and conclusion The current person-centred integrative diagnosis model argues for a broader concept of diagnosis and covers both ill health and positive health through the following three levels: Health Status (from illness to recovery/wellness and from disabilities to adaptive functioning), Experience of Health (cultural factors and values concerning ill health and positive health) and Contributory Factors (including internal and external risk and protective factors). Each of these domains will be evaluated with standardized categories and dimensions as well as narratives. Specific attention is paid to evaluators (clinicians, patient, family and other carers) and the interactive evaluation process.

Introduction

Person-centred clinical care proposes the whole person in context, as the centre and goal of clinical care and public health [1,2]. As diagnosis is a critical first step for clinical care, it was early recognized that an appropriate diagnostic model was necessary as informational basis for person-centred clinical care. Diagnosis has a fundamental role in medicine as the basic unit in the process of medical care. It is essential for communication among health professionals and other stakeholders; it is fundamental for the process of clinical care and the identification and treatment of disorders; it is used for prevention and health promotion, for conducting research, testing interventions and understanding disease mechanisms. Diagnosis is needed for education and training and for a host of administrative purposes from quality improvement to reimbursement activities. The pivotal role of diagnosis in the clinicians’ work was cogently expressed by Feinstein [3] as ‘Diagnostic categories provide the locations where clinicians store the observations of clinical experience’ and ‘The diagnostic taxonomy establishes the patterns, according to which clinicians observe, think, remember and act’. As diagnosis is a critical first step for clinical care, it was early recognized that an appropriate diagnostic model was necessary as informational basis for person-centred clinical care.

This manuscript presents key concepts, evolving structure and design of the person-centred integrative diagnosis (PID) model, including the primary components of this model: multi-level domains of health status, descriptive tools and evaluators (the protagonists of the diagnostic process).

Key concepts

The 20th century Spanish philosopher and humanist, Ortega y Gasset (1883–1955), dictum ‘I am I and my circumstance’ cogently captures the overarching concept embodied in the PID of considering ‘the whole person in context’, as the centre and goal of clinical care and public health. The key concept in the PID is its consideration of a broader and deeper notion of diagnosis (to include positive and ill aspects of health), which goes beyond the restricted concept of nosological diagnoses. The notion of diagnosis as a formulation of health status, and as a process involving the interactive participation and engagement of clinicians, patients and families, represents a paradigm shift.

The concept of diagnosis in the PID is to provide broader understanding of the person’s health status, describing both positive and ill health (disorders and disabilities as classified by the International Classification of Diseases and its national and regional adaptations), and to also include an innovative focus on positive aspects of health such as adaptive functioning, protective factors and quality of life, deemed crucial for enhancing recovery and health restoration.
A broader perspective on the meaning of diagnosis may also be gleaned from its etymological roots. Diagnosis has been derived from two connotations. On the one hand, diagnosis is derived from the Greek word ‘dia’, which refers to elucidating a disorder, a meaning that is more consonant with the common etiopathogenic meaning of diagnosis. The other term, also from the Greek language, is ‘diagignoskein’ which refers to the understanding of the person, reflecting the meaning of health (sanscrit hal) as wholeness. This latter definition is particularly suitable for chronic diseases, such as diabetes, hypertension or obesity, where behavioural components can assume significant role.

Reflecting on the meaning of diagnoses in medicine, the medical historian Lain-Entralgo stated that, ‘diagnosis is more than identifying disorders (nosological diagnoses)’, or ‘distinguishing one disorder from another (differential diagnosis); diagnosis is really understanding what is going on in the mind and body of the person who present for care’ [4]. A broader understanding of diagnosis that goes beyond the ethiopathogenic understanding has been reflected in ancient traditional medicine as well as in modern understanding of health. For example, in the ancient Chinese medicine, diagnostic indicators were always viewed holistically. The Indian medical tradition, Ayurveda, which means the science of living, views health as harmony between body, mind and spirit. Pointedly, in modern times, the World Health Organization Constitution defines health as ‘Health is a state of complete physical, emotional, and social well being, and not merely the absence of disease’ [5–8].

A second key concept of the PID is its emphasis on an inclusive and egalitarian process, highlighting the importance of all protagonists of the clinical encounter into the diagnostic process. Diagnostic formulation in the PID is also considered an ongoing process constructed through interactive partnership involving a dialogue between the primary stakeholders and evaluators. This partnership of equals includes the clinician (the conventional expert), the patient (the protagonist, informationally and ethically), the family (crucial support group) and community members (teachers, social workers, etc.). Thus, the PID, through this process, upholds the dignity, values and aspirations of the person seeking care.

**Multi-level person-centred integrative diagnosis model**

The design of a PID model was based on literature reviews and work meetings in London, Paris, Geneva, Preston, UK and Uppsala, Sweden over the past 2 years. It was also based on the well-established record of the World Psychiatric Association’s experience in the development of diagnostic models and contributions to the central issue of international diagnoses in psychiatry [9]. This is exemplified by the publication of the World Psychiatric Association’s International Guidelines for Diagnostic Assessment (IGDA) [10]. The IGDA has been widely accepted and adopted into regional settings, as illustrated by the Latin American Guide for Psychiatric Diagnosis [11], which is used in different countries in Latin America.

**Person-centred integrative diagnosis domains, schema, tools and evaluators**

The current organizational scheme of the developing multi-level PID model proposes to assess the health status of the person presenting for care, as opposed to a predominant focus on pathology. Thus, the two broad domains covered are ill health and positive aspects of health. In each of these domains, the PID schema provides for a standardized component and for a narrative, idio- graphic personalized component. The integration of these domains and components aims at forming the informational bases for intervention and care, such as developing treatment plans to guide recovery and health restoration, in addition to providing the informational bases for education, public health planning and for administrative functions.

The evolving PID model has currently three main levels within each health status domain (ill health vs. positive health status domains) [12]. Within the ill health status domain, the first level is ill health and its burden. This is further divided into two sub-levels: the first sub-level corresponds to clinical disorders, both mental and general health. The second sub-level corresponds to disabilities (regarding self-care, occupational functioning, functioning with family and participation in community activities). The second ill health domain level corresponds to the idiographic personalized narrative covering the experience of illness. This includes topics such as sufferings, values and cultural experience of illness and care. The third level within the ill health domain covers risk factors and contributors to ill health. These include inner risk factors such as genetic vulnerability and external risk factors such as stressors. Factors in this domain may also be conceptualized using a biopsychosocial framework.

Wellness is the first level of the positive health status domain. This is further divided into two sub-levels: the first sub-level corresponds to remission/recovery (health restoration and growth), while the second sub-level corresponds to functioning. The second level of positive health domain corresponds to the idiographic personalized narrative covering the experience of health. This includes topics such as quality of life, values and cultural formulation of identity and context. The third level in the positive health status domain covers protective factors and contributors to positive health. These may include inner protective factors such as resilience, and external protective factors such as social support. These factors may also be conceptualized in a bio-psycho-social framework (Fig. 1).

**Descriptive tools of the PID model**

Categories, as key descriptor of both ill health and positive aspects of health, will be used, particularly of a probabilistic type. Dimensions, as descriptive tools, will offer the opportunity to measure particular domains in a more quantitative manner. The richness and availability of information will also allow for categorical assignments above a certain threshold level. The use of narrative as descriptive tool would offer the possibility of a deeper and richer description of a relevant domain. This narrative component may also have therapeutic implications as it may foster more meaningful commitment to care by persons seeking help as they elaborate to create counter-balancing narratives for their respective experiences of illness and of health.

Evaluators involved in the diagnostic process constitute the third pillar of the PID. While the role of diagnostic evaluators has had limited attention outside certain themes addressing therapeutic, within the PID, evaluators’ role has been elaborated as ‘Triologs’ among patients, families and health professionals [13]. The patient as the main protagonist, both for informational source

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and as centre of ethical clinical care, the family and/or other important participants as source of support, the carers and pertinent community representatives (e.g. teachers for child diagnosis), and the clinicians as the trained experts constitute the evaluators team, which jointly would undertake the diagnostic process and formulate planned interventions.

**Future development of the person-centred integrative diagnosis**

Development of the PID has been a reiterative process with continuing refinements. Further development will involve the construction of a practical guide and application manual which will include translation and specification of the theoretical model into a set of procedures for practical use. The draft of the PID guide will include its structure and schema, along with the instruments to be used, and the descriptions of the assessment procedures. The feasibility, reliability and validity of the PID draft will then be evaluated through field trials across different realities and settings and a final version will be produced based on the results of the evaluation process and on expert discussions and input from health stakeholders.

**Conclusion**

The PID is a novel model of conceptualizing the process and formulation of clinical diagnosis. It proposes to implement into regular clinical practice the principles and vision of person-centred clinical care. The PID entails a broader and deeper notion of diagnosis, beyond the restricted concept of nosological diagnoses. It involves a multi-level formulation of health status (both ill and positive aspects of health) through interactive participation and engagement of clinicians, patients and families using all relevant descriptive tools (categorization, dimensions and narratives). The PID model is intended to be used in diverse settings across the world and to serve multiple needs in clinical care, education, research and public health.

**References**

From the Second Geneva Conference on Person Centered Medicine

Person-Centered Medicine: From Concepts to Practice

The Multicultural Quality of Life Index: presentation and validation

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Keywords

comprehensive diagnosis, culture, person-centred care, quality of life, scales, validation

Abstract

Rationale and objectives Quality of life has emerged as a crucial concept for the assessment of health and the planning of health care. Desirable features for the evaluation of quality of life include comprehensiveness, self-ratedness, cultural sensitivity, practicality and psychometric soundness. An attempt to meet these challenges led to the development of a brief multicultural quality of life instrument and to the appraisal of its applicability, reliability and validity.

Methods The development of the proposed assessment instrument was based on a wide review of the literature and the engagement of a multicultural mental health scholarly team. Its validation was conducted on samples of psychiatric patients (n = 124) and hospital professionals (n = 53) in New York City.

Results A new generic culture-informed and self-rate instrument, the Multicultural Quality of Life Index, has been developed. Its 10 items cover key aspects of the concept, from physical well-being to spiritual fulfilment. Concerning its applicability, mean time for completion was less than 3 minutes and 96% of raters found it easy to use. Test–retest reliability was high (r = 0.87). A Cronbach’s α of 0.92 documented its internal consistency and a factor analysis revealed a strong structure. With regard to discriminant validity, a highly significant difference was found between the mean total scores of professionals (x̄ = 8.41) and patients (x̄ = 6.34) presumed to have different levels of quality of life.

Conclusions The Multicultural Quality of Life Index is a brief and culturally informed instrument that appears to be easy to complete, reliable, internally consistent and valid.

Introduction

Quality of life is rapidly becoming one of the key concepts in the health field. Since the 1970s, interest in the assessment of quality of life has been growing, initially with reference to individuals experiencing oncologic and other chronic general medical illnesses. In more recent years, such interest has become conspicuous also in psychiatry and mental health [1]. This interest has been accompanied by increased attention to social functioning, social support and other positive aspects of health relevant to both clinical care and epidemiological work [2,3]. The assessment of quality of life is being regarded as a substantial parameter for comprehensive diagnostic assessment and to evaluate the effectiveness of health care [4]. Illustrating advances in diagnostic systems, the World Psychiatric Association International Guidelines for Diagnostic Assessment (IGDA) [5] has included quality of life as a separate diagnostic axis.

While the notion of quality of life is acquiring a prominent place in the health field, its definition and the approaches to its assessment are still under intense discussion. It has been argued that quality of life is a term that describes a field of interest rather than a single variable. Besides, the challenge represented by the appraisal of quality of life is becoming increasingly daunting as modern societies have become more heterogeneous and widely multicultural. Despite such difficulties, interest on quality of life has not abated, and there are compelling reasons that justify its use in the quest for more competent and culturally sensitive health care.
The current concept of quality of life has evolved from two different sources: the health-related functional status indexes and the social science indexes. It has been pointed out that the fact that these two sources involve disparate approaches and concepts may contribute to confusion on the definition and measurement of quality of life [6]. Thus, a meaningful integration of both perspectives is desirable.

Currently, many instruments designed to measure quality of life are available. They may be roughly divided into generic and disease specific. Detailed and useful comparisons of some of these instruments, in terms of scope, design, dimensions and psychometric soundness have been published [7]. Some preliminary reviews suggested that depending on its intended use, a well-rounded instrument should assess at least the following five life domains of personal experience: biological, psychological, interpersonal, social and economic [8].

A critical review of the international literature identified the following key desirable characteristics for instruments designed to assess quality of life: (1) Cultural applicability: sensitivity to ethnic diversity and ability to take into account cultural background in order to rate quality of life in a meaningful way. (2) Comprehensiveness: coverage should go beyond physical and emotional well-being, to encompass a broad concept of health including social functioning and supports, personal aspirations and spiritual fulfillment. (3) Wide applicability: it should be useful and relevant for diverse populations and settings, including people experiencing both general medical and psychiatric conditions. (4) Self-ratedness: this recognizes the predominantly subjective nature of quality of life and the crucial perspective of the person whose life is being assessed. (5) Ease of use: this is of decisive practical value particularly in busy health care settings. (6) Sound psychometric features: including reliability or generalizability as well as validity or usefulness.

The following sections describe the process and results concerning the development of the Multicultural Quality of Life Index (MQLI) as an attempt to meet the above listed goals, and then its validation in terms of feasibility, reliability, internal consistency and discriminant validity.

**Design and presentation of the Multicultural Quality of Life Index**

**Identification of key dimensions**

In order to incorporate the conceptual complexity of quality of life into the instrument to be developed, an exploration of relevant dimensions was conducted through a review of the international literature. Attention was focused on reports presenting substantial discussions of the concept of quality of life or comprehensive instruments for its assessment. Table 1 displays 21 reports [9–29] concerning instruments or approaches for the assessment of quality of life and the categorized dimensions of the concept that each report encompasses. This categorization was based on a thematic analysis of the identified dimensions. The obtained themes are presented on the first column of the table, and can be summarized as follows: physical and emotional health; functioning in terms of autonomy, self-care, occupational and interpersonal roles; social-interpersonal and environmental-material support; personal purposefulness, wholeness and enjoyment; spirituality, sense of transcendence, religiousness; and global appraisal of quality of life.

As can be seen in Table 1, all the dimensions elicited had multiple endorsements in the reviewed literature, that is, each was included in at least 6 of the 21 reports. The three most frequently mentioned dimensions were physical health, psychological health and interpersonal functioning (19 reports each), followed by occupational functioning (17 reports). These dimensions, in fact, refer to the more conventional aspects of health, revealing that the reviewed literature deals predominantly with the notion of health-related quality of life. Next in frequency were social-interpersonal supports (16 reports) and various facets of environmental and material support (jointly 15 reports), which correspond to the context of the individual, and have become accepted as significant elements of health status [30]. Somewhat less frequent, but still substantial in endorsement, are, on one hand, personal purposefulness, wholeness and enjoyment (jointly 13 reports), and on the other, spirituality, sense of transcendence and religiousness (8 reports), which together correspond to more subtle but not less important recently incorporated aspects of health [31]. Of note, attention to personal aspirations and spirituality represent distinct contributions from the developing world and traditional societies towards a more encompassing assessment of quality of life [32]. Finally, six of the reviewed multidimensional approaches included global self-assessment of quality of life, which points out the value accorded to the self-perceptions of the individual as the immediate and principal arbiter of quality of life.

Working on the literature review summarized on Table 1, the various dimensions corresponding to environmental-material support were clustered and consolidated into ‘community and services support’, and those on personal purposefulness, wholeness and enjoyment into ‘personal fulfillment’. The result was the following 10 dimensions of quality of life:

1. Physical Well-being (feeling energetic, free of pain and of physical problems)
2. Psychological/Emotional Well-being (feeling good, comfortable with yourself)
3. Self-care and Independent Functioning (carrying out daily living tasks; making one’s own decisions)
4. Occupational Functioning (able to carry out work, school and homemaking duties)
5. Interpersonal Functioning (able to respond and relate well to family, friends and groups)
6. Social Emotional Support (availability of people you can trust and who offer help and comfort)
7. Community and Services Support (good and safe neighborhood, availability of resources, and other services)
8. Personal Fulfillment (experiencing a sense of balance, solidarity, and empowerment; enjoying sexuality, aesthetics, etc.)
9. Spiritual Fulfillment (having a high philosophy of life; religiousness; transcendence beyond ordinary material life)
10. Overall Quality of Life (feeling satisfied and happy with your life in general)

**Development of other language versions**

The design of MQLI took place in a multicultural and multilingual professional matrix in New York as represented by the members of
### Table 1 Dimensions of quality of life elicited from the international literature

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<td>Safety</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Other environmental-material support</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Personal purposefulness</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Personal wholeness</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Personal enjoyment</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Spirituality, transcendence, religiousness</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Global appraisal of life</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>
The Multicultural Quality of Life Index

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our research team. This included native speakers of Spanish, English, Korean, Chinese and South Asian languages. Such matrix facilitated the conceptualization of a culturally suitable index and the development of several language versions. More specifically, four language versions were developed and studied, as follows. The English and Spanish versions [33] were developed simultaneously, while the Chinese [34] and Korean [35] versions were developed through a process of translation and back-translation related to the English version.

Rating approach

The 10 items of the MQLI were designed to cover well the rich conceptual framework resulting from the literature review. The items names were carefully and concisely phrased. The prompts within parentheses offer a brief explanation of each concept. This simplicity was intended to allow the person completing the instrument a measure of flexibility to rate each item according to his or her cultural and experiential background. This simplicity and flexibility, in fact, represent critical features of the MQLI, maximizing in each use its cultural relevance. Also, helpful from a transcultural comparability perspective is that the text of the instrument has been formulated by a multilingual team speaking English, Spanish, Chinese and Korean. This minimized the emergence of biases usual in the translation and adaptation of health instruments [36,37] and moderated the emergence of biased results from cross-cultural and cross-lingual assessment [38].

The quantification of the standing of the individual on each quality of life dimension is obtained through his or her ratings and markings on a 10-point scale ranging from poor to excellent. The MQLI final score is obtained by computing the average of the scores (1–10) of all the items actually rated by the individual.

Presentation of the form for the Multicultural Quality of Life Index – English version (MQLI-En)

The format for the MQLI-En was produced on the basis of the selected dimensions of quality of life and the rating approach outlined in the preceding section. It is presented as Fig. 1. The form also includes the subject’s demographic information, monitor’s name and date. The role of the monitor is simply to present the form to the subject, answer general questions and encourage the subject to complete the procedure. The form contains instructions for filling out the MQLI-En and a slot for recording the final score as the average of the completed item ratings.

Validation of the Multicultural Quality of Life Index – English version

Method of the Validation Study

Location of the Validation Study

The study was conducted at Elmhurst Hospital Center, a large general hospital located in Elmhurst, Western Queens, New York City, and a campus of the Mount Sinai School of Medicine, New York University. It is the main health care resource for a highly multicultural community. Elmhurst-Jackson Heights is regarded as one of the ethnically most diverse areas of the world.

Subject samples and their demographic distribution

To address the research validation questions, two cross-ethnic English speaking samples with presumed different levels of quality of life were recruited at Elmhurst Hospital Center. One was composed of adult psychiatric patients receiving care in one of various psychiatric services and the other was composed of actively working health professionals (doctors, nurses, psychologists, social workers and administrative staff). Subjects were 18 years of age or older, of either gender, capable of communicating in English, and willing to provide informed consent to participate in the study.

The psychiatric patient sample was composed of 124 individuals (41.1% female and 58.9% male) with a mean age of 36.9 years (SD = 14.7). The health professional sample was composed of 53 individuals (58.5% female and 41.5% male) with a mean age of 38.2 years (SD = 10.1). Patients and professionals did not differ significantly in age (t = 0.665, d.f. = 136.793, P = 0.507), but differed in gender distribution (χ² = 4.501, d.f. = 1, P = 0.034). The mean educational level of the total sample was 13.58 years of education (SD = 1.26). Patients (mean = 12.14, SD = 3.76) and professionals (mean = 17.10, SD = 3.3) differed significantly in their level of education (t = 7.978, d.f. = 164, P < 0.001). The ethnic breakdown of the total sample was 37.3% White, 36.2% Hispanic, 15.3% Asian, 8.5% Black and 1.1% of other ethnicity.

Evaluation procedures and data collection

The sampled psychiatric patients were initially informed about the study by a treating clinician and those interested in participating were introduced to research assistants trained to monitor the completion of the instrument. Participation was voluntary, virtually no subject declined to participate, and written informed consent was obtained from all subjects at the time of enrolment through protocols approved by the local Institutional Review Board. Information relevant to the feasibility, reliability, internal structure and discriminant validity of the MQLI-En was collected and statistically analysed.

Validation results

Feasibility

Concerning time to complete the MQLI-En, the average time taken by patients was 2.4 minutes (SD = 1.3, range: 0.83–15 minutes) and by professionals 1.3 minutes (SD = 0.5, range: 0.58–4.3 minutes). The samples differed significantly in the time needed to complete it (t = −7.660, d.f. = 174.24, P < 0.001). In the combined sample, the average time was 2.03 minutes (SD = 1.3, range: 0.58–15 minutes).

With reference to ease of use of the MQLI-En, Table 2 presents the distribution of this variable as perceived by the subjects and the monitors. The vast majority of subjects and monitors (over 96% of them) perceived the MQLI-En as very easy or somewhat easy to use (as opposed to somewhat difficult or very difficult to use).
Multicultural Quality of Life Index
(Mezzich, Cohen, Ruipérez, Liu & Yoon, 1999)

Subject Name: _____________________________  Subject Code: ____________
Age: _____ years  Gender: ☐ Female ☐ Male  Interviewer: _____________
Ethnic group: ______________________________  Date: ___________________

Instructions: Please indicate the quality of your health and life at present, from “poor” to “excellent”, by placing an X on any of the ten points on the line for each of the following items:

1. Physical Well-being (feeling energetic, free of pain and physical problems)
  Poor 2 3 4 5 6 7 8 9 10 Excellent

2. Psychological/Emotional Well-being (feeling good, comfortable with yourself)
   Poor 2 3 4 5 6 7 8 9 10 Excellent

3. Self-Care and Independent Functioning (carrying out daily living tasks; making own decisions)
   Poor 2 3 4 5 6 7 8 9 10 Excellent

4. Occupational Functioning (able to carry out work, school and homemaking duties)
   Poor 2 3 4 5 6 7 8 9 10 Excellent

5. Interpersonal Functioning (able to respond and relate well to family, friends, and groups)
   Poor 2 3 4 5 6 7 8 9 10 Excellent

6. Social-Emotional Support (availability of people you can trust and who can offer help and emotional support)
   Poor 2 3 4 5 6 7 8 9 10 Excellent

7. Community and Services Support (pleasant and safe neighborhood, access to financial, informational and other resources)
   Poor 2 3 4 5 6 7 8 9 10 Excellent

8. Personal Fulfillment (experiencing a sense of balance, dignity, and solidarity; enjoying sexuality, the arts, etc.)
   Poor 2 3 4 5 6 7 8 9 10 Excellent

9. Spiritual Fulfillment (experiencing faith, religiousness, and transcendence beyond ordinary material life)
   Poor 2 3 4 5 6 7 8 9 10 Excellent

10. Global Perception of Quality of Life (feeling satisfied and happy with your life in general)
    Poor 2 3 4 5 6 7 8 9 10 Excellent

Figure 1 Format of the Multicultural Quality of Life Index.

Table 2 Ease of use of the Quality of Life Index – English version, as perceived by subjects and the monitors

<table>
<thead>
<tr>
<th>Degree of ease of use</th>
<th>As perceived by subjects</th>
<th>As perceived by monitors</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Patients (%) (n = 124)</td>
<td>Professionals (%) (n = 53)</td>
</tr>
<tr>
<td>Very easy</td>
<td>72.6</td>
<td>86.8</td>
</tr>
<tr>
<td>Somewhat easy</td>
<td>23.4</td>
<td>11.3</td>
</tr>
<tr>
<td>Somewhat difficult</td>
<td>4.0</td>
<td>1.9</td>
</tr>
<tr>
<td>Very difficult</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

*Valid percentages only, excluding missing values.
The internal consistency (Cronbach’s $\alpha$) of the MQLI-En was quite high in the combined sample ($\alpha = 0.92$), the professional sample ($\alpha = 0.91$) and the patient sample ($\alpha = 0.90$). The factor analysis (principal components method) of the MQLI-En’s 10 items in the combined sample of 177 patients and professionals, presented in Table 3, yielded one single factor, which accounted for a remarkable 59.34% of the items’ variance. Furthermore, the totality of the MQLI-En items had loadings above 0.6 on this factor.

Test-retest reliability

The MQLI-En was applied twice to subsamples of patients ($n = 124$) and professionals ($n = 53$) (20 of the 53 professionals participating in the study were not available to complete retest exercises) with an interval between test and retest of 1–15 days (mean interval: 5.32 days; SD = 2.13) to assess instrumental reliability or generalizability in terms of correlation coefficients calculated for individual items and the main average score. As shown on Table 4, the reliability coefficients were quite substantial for individual items, ranging from 0.67 to 0.79 (significantly different from zero at $P < 0.01$) and it reached 0.87 ($P < 0.01$) for the average score.

Discriminant validity

The discriminant validity results for the MQLI-En are presented on Table 5. A significant difference ($P < 0.001$) was found between the mean average score of patients (mean = 6.34, SD = 1.77) and professionals (mean = 8.41, SD = 0.92) ($t = 10.194$, d.f. = 168.322, $P < 0.001$), presumed to have different quality of life levels. Significant differences between the two samples were also found for every single item.

Discussion

A comparison of the MQLI design features against the list of critical issues for the assessment of quality of life presented earlier in this paper stimulates the following comments.

Concerning comprehensiveness, the MQLI-En and its 10 individual items, despite its brevity, reflect virtually all important aspects of quality of life reported in the international literature,

Table 3  Factorial structure of the Quality of Life Index – English version on a combined sample of English-speaking patients ($n = 124$) and professionals ($n = 53$)

<table>
<thead>
<tr>
<th>Items</th>
<th>Factor loadings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Physical well-being</td>
<td>0.71</td>
</tr>
<tr>
<td>2. Psychological/emotional well-being</td>
<td>0.84</td>
</tr>
<tr>
<td>3. Self-care and independent functioning</td>
<td>0.81</td>
</tr>
<tr>
<td>4. Occupational functioning</td>
<td>0.77</td>
</tr>
<tr>
<td>5. Interpersonal functioning</td>
<td>0.73</td>
</tr>
<tr>
<td>6. Social emotional support</td>
<td>0.73</td>
</tr>
<tr>
<td>7. Community and services support</td>
<td>0.75</td>
</tr>
<tr>
<td>8. Personal fulfilment</td>
<td>0.81</td>
</tr>
<tr>
<td>9. Spiritual fulfilment</td>
<td>0.66</td>
</tr>
<tr>
<td>10. Global perception of quality of life</td>
<td>0.86</td>
</tr>
</tbody>
</table>

Variance accounted for: 59.34%

K-M-O measure of sampling adequacy = 0.937.

Bartlett’s test of sphericity: $\chi^2 = 1031.8$, d.f. = 45, $P < 0.001$.

Table 4  Test-retest reliability coefficients for the Quality of Life Index – English version on a combined sample of English-speaking patients ($n = 124$) and professionals ($n = 53$)

<table>
<thead>
<tr>
<th>Items</th>
<th>Correlation coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Physical well-being</td>
<td>0.74</td>
</tr>
<tr>
<td>2. Psychological/emotional well-being</td>
<td>0.79</td>
</tr>
<tr>
<td>3. Self-care and independent functioning</td>
<td>0.69</td>
</tr>
<tr>
<td>4. Occupational functioning</td>
<td>0.76</td>
</tr>
<tr>
<td>5. Interpersonal functioning</td>
<td>0.67</td>
</tr>
<tr>
<td>6. Social emotional support</td>
<td>0.69</td>
</tr>
<tr>
<td>7. Community and services support</td>
<td>0.72</td>
</tr>
<tr>
<td>8. Personal fulfilment</td>
<td>0.72</td>
</tr>
<tr>
<td>9. Spiritual fulfilment</td>
<td>0.79</td>
</tr>
<tr>
<td>10. Global perception of quality of life</td>
<td>0.73</td>
</tr>
</tbody>
</table>

Average score 0.87

Table 5  Discriminant Validity of the Quality of Life Index – English version, indicated through the comparing of mean scores between English-speaking patients and professionals on individual items and the main average score

<table>
<thead>
<tr>
<th>Items</th>
<th>Patients ($n = 124$) Mean (SD)</th>
<th>Professionals ($n = 53$) Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Physical well-being</td>
<td>6.27 (2.49)</td>
<td>7.89 (1.19)</td>
</tr>
<tr>
<td>2. Psychological/emotional well-being</td>
<td>6.10 (2.48)</td>
<td>8.09 (1.39)</td>
</tr>
<tr>
<td>3. Self-care and independent functioning</td>
<td>6.74 (2.29)</td>
<td>9.00 (1.02)</td>
</tr>
<tr>
<td>4. Occupational functioning</td>
<td>6.20 (2.50)</td>
<td>8.98 (0.97)</td>
</tr>
<tr>
<td>5. Interpersonal functioning</td>
<td>6.43 (2.42)</td>
<td>8.64 (1.40)</td>
</tr>
<tr>
<td>6. Social emotional support</td>
<td>7.06 (2.33)</td>
<td>8.51 (1.35)</td>
</tr>
<tr>
<td>7. Community and services support</td>
<td>6.64 (2.48)</td>
<td>7.96 (1.53)</td>
</tr>
<tr>
<td>8. Personal fulfilment</td>
<td>5.56 (2.42)</td>
<td>8.40 (1.03)</td>
</tr>
<tr>
<td>9. Spiritual fulfilment</td>
<td>6.38 (2.56)</td>
<td>8.40 (1.10)</td>
</tr>
<tr>
<td>10. Global perception of quality of life</td>
<td>5.95 (2.61)</td>
<td>8.23 (1.33)</td>
</tr>
<tr>
<td>Overall average score</td>
<td>6.34 (1.77)</td>
<td>8.41 (0.92)</td>
</tr>
</tbody>
</table>

* $P < 0.001$ (two-tailed) for all patient–professional differences.
from conventional physical and emotional well-being, to various aspects of functioning, social and environmental context, personal and spiritual fulfilment and global self-assessment.

Regarding evaluators, in line with the predominantly subjective nature of the quality of life concept, the MQLI-En is to be completed directly by the subject. However, the development of complementary versions to be completed by clinicians, family members and caregivers may be worth exploring, particularly, when subjects have difficulty completing self-evaluations.

Cultural suitability was also attended to in instrument development. First, its content reflected perspectives elucidated from across international and multicultural settings. The multilingual process employed for the development of the various language versions of the instrument also speaks to the engagement of cultural diversity. The various language versions of the MQLI (English, Spanish, Chinese, Korean, Portuguese, German) are being studied in New York and in other parts of the world [33, 39–44]. Furthermore, the MQLI-En, with its minimal definition of each dimension has the potential to promote the subjects’ interpretation and rating of the dimensions in consonance with their own cultural framework.

In regard to generic versus disease-specific applicability, the MQLI-En can be recognized as a generic instrument for person-based assessment of quality of life across different clinical conditions and settings. This was shown by studies with subjects with multiple sclerosis [44], sleep disorders [45] and AIDS [42]. As a generic instrument, the MQLI focuses the evaluation on the person at hand (who is the centre and agent of quality of life) rather than on illnesses present. Further to note is the use of the MQLI in community settings [46, 47].

Rapid administration time (1–3 minutes) and ease of administration, as efficiency indicators documented in this study, are distinct assets of the MQLI-En. Efficiency under additional clinical and socio-cultural situations could be usefully explored.

The substantial test–retest reliability obtained empirically in this study is quite encouraging, particularly considering the definitional flexibility allowed for the sake of cultural suitability. One could argue that the test–retest interval (1–15 days) may have been too short in some cases. On the other hand, lengthening this interval may have complicated the retention of research subjects.

Discriminant validity is a major evaluative aspect. The highly significant difference found between samples with presumably different levels of quality of life documented the discriminant validity of the MQLI-En. Other validational strategies, such as assessment of convergence validity between the MQLI and more extensive instruments (e.g. The Lehman’s Quality of Life Inventory) [12] are also being studied and presented elsewhere.

A review of the numerous published instruments to assess quality of life (as compared to the MQLI) did not yield instruments that appeared to be equally comprehensive in their scope (from physical well-being to spirituality) as well as simultaneously fast and easy in its administration.

Future developmental and research work with the MQLI may valuably include the following:

1. Preparation and validation of various language-versions of the MQLI, in addition to the Spanish, Korean and Chinese versions presented elsewhere, relevant to prominent populations in the very ethnically diverse Jackson Heights-Elmhurst area of New York City, as well as, through collaboratory arrangements, in other parts of the world.

2. Development of MQLI versions for the use of complementary evaluators, such as clinicians, family members and caregivers. These would have the same basic content and format as the principal MQLI, to facilitate integration and comparison of results, as well as incorporate adjustments in the instructions for completing the form.

3. To understand more deeply the results yielded by the MQLI, the identification of the quality of life dimensions most important or meaningful for a given person could be ascertained. One efficient and indirect approach would involve identifying, on a completed MQLI form, the dimensions having the closest ratings to his or her global perception of quality of life. Subjects could also be asked to undertake the additional rating step of circling the dimensions most meaningful to them, as well as to engage in narrative elaboration of their perceived quality of life given that numerical ratings do not allow the understanding that stories can offer.

Conclusions

The results of the development and validation of the MQLI suggested that it is one of the most comprehensive in scope (from physical to spiritual aspects), and, at the same time, highly efficient (taking few minutes to be completed). The psychometric testing of the English version has documented its test–retest reliability, internal consistency and discriminant validity. Additionally, the MQLI seems to facilitate subjects to respond and rate their quality of life according to their cultural framework. A number of recent publications provide evidence of the relevance of the MQLI to assess quality of life in people experiencing a range of psychiatric and general medical clinical conditions as well as in epidemiological surveys. Therefore, the instrument may be useful in both clinical and community settings.

Acknowledgements

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References


The Multicultural Quality of Life Index

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Prospects for person-centred diagnosis in general medicine

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Keywords
biopsychosocial model, health information technology, patient-centred health care, patient-centred medical home, person-centred care, primary health care

Abstract
Fundamental changes in health care delivery are revealing the limitations of our collective focus on disease-specific and technology-driven health care. We increasingly treat diseases, not persons, and it moves individuals from active participants in the care process to passive recipients of interventions. This problem is especially important for general medicine, where we must maintain the balance between person and disease, caring and technology. In this chapter, we focus on prospects for person-centred diagnosis and treatment in general (primary care) medicine in this time of change. We describe one way to employ the biopsychosocial model to integrate person-centred diagnosis in routine clinical practice, and we propose a ‘person-centred path’ for primary care development with the health information technology tools we will need to develop to follow that path.

Introduction
We are now in a time of great and fundamental change in health care delivery. Developed nations are struggling to harness health care technology so that its overuse does not bankrupt national economies. We are seeing the limitations of our collective focus on disease-specific and technology-driven care. We treat diseases, not persons, and it moves individuals from active participants in the care process to passive recipients of interventions. At the same time, developing nations are looking to developed nations for assistance in organizing systems of care and implementing health information technology, and are at risk of building systems that will only reproduce the problems faced in the developed world.

These struggles are particularly relevant to the future of primary health care. Everywhere in the world, from highly developed health care delivery systems to developing regions, primary health care has the same purpose – to meet the needs of persons living in the community. In primary care we must maintain the balance between person and disease, caring and technology.

In this chapter, we focus on prospects for person-centred diagnosis and treatment in general (primary care) medicine in this time of change, and how we might integrate the person into our evolving health care technology infrastructure.

The core task(s) of primary health care
Although the specific circumstances and processes of medical care vary from country to country, the core tasks of family doctors/general practitioners are the same:
• To understand the full range of clinical problems faced by patients;
• To know the social and personal context in which these problems occur;
• To take into account patients’ own priorities and goals when making decisions about treatment;
• To carry out preventive services and help patients identify and manage health risks.

These tasks are accomplished in a stream of encounters over time, during which circumstances, priorities, clinical knowledge and ‘rules’ are moving targets. Much of the work of primary care clinicians is in establishing and updating priorities for care, as it is rare that patients present with only one clinical problem. To do this right requires that clinicians operate using a person-centred approach.

But the person-centred approach requires time – and time is the most limited resource in the current world of health care delivery. Published studies confirm that primary care clinicians have between 7 and 20 minutes per encounter to address 2–7 distinct
problems, with an average of 4 minutes of time to spend per problem [1–3]. Because most encounters are driven by patient demand to address acute problems or concerns, where can clinicians find the time required to address prevention, documentation, and handle administrative services? While these issues affect all of general medicine, primary care presents the most difficult set of problems. Primary care clinicians cope by ‘satisficing’ [4–6] – using quick decision strategies based on incomplete information that are ‘good enough’ most of the time, then using time to sort out those problems that require special care. Primary care clinicians also satisfice when they assign formal diagnoses at clinical encounters. They use short cuts. They don’t care so much about precision. They don’t memorize the long and arbitrary criteria lists required to assign many current mental health diagnoses [7–9].

Given this situation, how can we accommodate the additional work of learning about the context of patient’s lives – and their preferences, priorities and goals for treatment?

The current situation: chaos and the promise of the patient-centred medical home (PCMH)

In the USA, and to some degree in other developed countries, the coping strategies listed above are becoming more difficult to maintain for several reasons:

- Information overload on specific clinical problems (new guidelines, new treatment recommendations, new data) has outpaced information management strategies;
- Lack of knowledge about how clinical problems interrelate makes much of the available information irrelevant to managing patients in the ‘real world’;
- Increased time and effort required to manage complex health information technology software [most notably ambulatory electronic health records (EHRs)] has had far greater negative impact on primary care than specialty care [10–12];
- The current generation of EHRs do not readily accommodate patient-side data such as the stated reason(s) for encounter, patients’ own priorities and goals, or relevant social context;
- Coordination of information – and care – between primary and specialty practice has become more important, and is unsupported by a visit-based reimbursement system and stand-alone EHR products;
- The growing effort to move mental health care into the general medical setting while maintaining specialty-based standards has added new tasks without providing additional support.

In light of these events, many primary care clinicians are retreating into a more narrow focus on current clinical problems and on improving those outcomes of care that can be measured. This makes implementing patient-centred care far more difficult.

But there is hope for the person-centred approach. Recently in the USA there has been a great deal of discussion about the PCMH. This label covers a large portfolio of related changes in health care delivery, with the goal of transforming the health care system (hospitals, home health agencies, nursing homes, consultants and other components of the complex health care system), facilitated by registries, information technology, health information exchange and other means to assure that patients get the indicated care when and where they need and want it [13].

This definition provides a roadmap to develop the tools and processes necessary to implement person-centred medicine in the USA, and it is one of the innovations at the centre of the U. S. health care reform effort [14–16]. It may also work for developed health care markets elsewhere. But it will require a major transformation in how health care is organized and how primary care clinicians are reimbursed for the services they provide.

A conceptual model for person-centred diagnosis in general medical practice

Primary care patients frequently present for care with a mixture of psychological, physical and social problems. Our reductionistic scientific model copes with this phenomenon by viewing medical care through the lens of a single disease and labelling other diseases and problems as ‘co-morbidity’ to be addressed after the ‘primary’ disease or condition. While this approach may work for specialty-based medical care, it does not work well in general medical settings. ‘Co-morbid’ conditions may be related through common causal pathways, but more often are coincidental [17]. Mental health and general medical co-morbidities, along with social problems, are the rule rather than the exception in persons presenting to primary care clinicians. They are such a part of the fabric of routine general medical practice that the use of the term ‘co-morbidity’, which implies sporadic co-occurrence of independent conditions, is potentially very misleading. Our understanding of primary care might be enhanced by replacing ‘co-morbidity’ with ‘multi-morbidity’ and focusing effort on the integration of diagnosis and treatment across domains [18–20].

It can be useful to visualize this ongoing interaction among general health problems, mental health problems and social problems in a three-dimensional biopsychosocial space [21]. In this space, the severity or level of problems in each domain at a single point in time can be plotted on an axis (Fig. 1) as a rough estimate of the overall burden of illness. Over time, the position of the point on each axis will change.

As the biopsychosocial model [22] would predict, these three domains are highly correlated. Mental health problems are known to occur more frequently in those with common chronic physical illness, such as diabetes, arthritis and heart disease [23–27], general medical conditions affect how persons experience and cope with their mental health problems [26,28,29], and the presence of social

A medical practice that operates as a PCMH consists of the personal doctor leading a team of health care professionals who collectively take responsibility for the ongoing care of the patient.

A whole person orientation is a key component of the PCMH. The personal doctor is responsible for providing for all the patient’s health care needs or taking responsibility for managing care with other qualified professionals. This includes care for all stages of life; acute care; chronic care; preventive services; and end-of-life care.

Care is coordinated across all elements of the patient’s community including the health care system (hospitals, home health agencies, nursing homes, consultants and other components of the complex health care system), facilitated by registries, information technology, health information exchange and other means to assure that patients get the indicated care when and where they need and want it [13].

This definition provides a roadmap to develop the tools and processes necessary to implement person-centred medicine in the USA, and it is one of the innovations at the centre of the U. S. health care reform effort [14–16]. It may also work for developed health care markets elsewhere. But it will require a major transformation in how health care is organized and how primary care clinicians are reimbursed for the services they provide.

A conceptual model for person-centred diagnosis in general medical practice

Primary care patients frequently present for care with a mixture of psychological, physical and social problems. Our reductionistic scientific model copes with this phenomenon by viewing medical care through the lens of a single disease and labelling other diseases and problems as ‘co-morbidity’ to be addressed after the ‘primary’ disease or condition. While this approach may work for specialty-based medical care, it does not work well in general medical settings. ‘Co-morbid’ conditions may be related through common causal pathways, but more often are coincidental [17]. Mental health and general medical co-morbidities, along with social problems, are the rule rather than the exception in persons presenting to primary care clinicians. They are such a part of the fabric of routine general medical practice that the use of the term ‘co-morbidity’, which implies sporadic co-occurrence of independent conditions, is potentially very misleading. Our understanding of primary care might be enhanced by replacing ‘co-morbidity’ with ‘multi-morbidity’ and focusing effort on the integration of diagnosis and treatment across domains [18–20].

It can be useful to visualize this ongoing interaction among general health problems, mental health problems and social problems in a three-dimensional biopsychosocial space [21]. In this space, the severity or level of problems in each domain at a single point in time can be plotted on an axis (Fig. 1) as a rough estimate of the overall burden of illness. Over time, the position of the point on each axis will change.

As the biopsychosocial model [22] would predict, these three domains are highly correlated. Mental health problems are known to occur more frequently in those with common chronic physical illness, such as diabetes, arthritis and heart disease [23–27], general medical conditions affect how persons experience and cope with their mental health problems [26,28,29], and the presence of social

A medical practice that operates as a PCMH consists of the personal doctor leading a team of health care professionals who collectively take responsibility for the ongoing care of the patient.

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problems or the occurrence of significant life events have a major impact on the severity of mental health problems or outcomes of care for chronic physical illness [30–32]. Over time, changes in the severity of general health problems may create additional social problems or intensify existing mental health problems, and increasing severity of mental health problems may amplify physical symptoms. Understanding and managing these interactions is a core part of the everyday work of a primary care doctor.

Here is an example of how this framework can help clinicians achieve person-centred diagnosis, from a recent half-day clinical session of one of the authors (MK).

• First patient of session: RN
  45-year-old man, to be seen for ‘cough’. He has a rare genetic syndrome causing pulmonary hypertension, multiple polyps, and predisposing him for cancers. Other active problems include asthma with recurrent bronchitis, chronic trunk/back pain, chronic airway problems with indwelling tracheostomy and MRSA colonization, toxic multinodular goiter, chronic depression, anxiety and sleep problems. He is married, has a young child with the same genetic disorder and ADHD. He is disabled, has done part-time volunteer work. He and his wife have significant relationship problems, and he has conflict with his extended family. He has extreme frustration with his limitations in health and function and chronic anxiety primarily related to his long-term health prognosis. The real reason for his visit is depression and relationship issues, worry and anger management.

Creating a 3D problem matrix for RN (Fig. 2) illustrates the severity of his problems in all dimensions. His medical problems are severe, but the added burden of his depressive and anxiety symptoms and social problems makes caring for this person a complex and difficult task. Given the range and severity of RN’s problems, it will be necessary to work with him to identify his primary goal(s) for care.

• Next patients in session: MS, MK, DA, JN, CM
  Each patient has a mix of medical, mental health and social problems: for example, MS has severe medical problems but minimal emotional or social problems, while DA is in crisis from relationship problems and social problems makes caring for this person a complex and difficult task. Given the range and severity of RN’s problems, it will be necessary to work with him to identify his primary goal(s) for care.

NOTE: Although person “B” is often considered to be the most severely ill in medical terms, the overall burden of illness is higher for persons A and C.
Person-centred, biopsychosocial diagnosis can be supported by use of this framework, but we are a long way from implementing this in a rigorous, quantitative fashion in everyday clinical practice. Although we have standard classification tools that can provide diagnostic codes for social problems (International Classification of Primary Care, to a lesser extent ICD-10) [21,33–35], primary care clinicians too often restrict their documentation to include only medical and mental health diagnostic coding. We will not be able to fully implement person-centred diagnosis until we make better use of these classification tools.

Two visions for person-centred diagnosis in general medicine in 2019

The disease technology path

This is what we will most likely experience if we continue on the path we have taken with its emphasis on the marketing of disease treatment (‘disease management’) to date, particularly in light of the health information technology (health IT) purchase incentives embedded in the American Recovery and Reinvestment Act of 2009.

• ‘Enterprise’ health IT products that are more expensive to purchase, more complex to use, more template-driven, based on an outdated disease-oriented data model;
• decision support based upon specific conditions rather than persons (disease management templates); OR
• decision support that requires accurate and specific data far beyond the level available in routine primary care (for ‘knowledge management’);
• quality assessment (and doctor payment) based on specific and measurable disease-specific outcomes;
• electronic Personal Health Records that are not interoperable with provider-side health IT;
• competition rather than collaboration, involving multiple vendors and for-profit entities.

The person-centred path

This is a high-risk path. It represents an extended version of an approach to health information technology that has attracted a growing number of advocates, from health informatics experts to practicing clinicians to large information management firms such as IBM. This vision is based upon use of simple, interoperable, open-source health IT products, known collectively as ‘clinical groupware’ applications [36,37].

How will we get there? Items needed for the person-centred ‘toolbox’ in general medicine

The challenge in front of us is to not settle for just identifying best practices and creating new standards for person-centred care. We’ve been there, done that – over and over – for specific clinical problems such as hypertension, with little impact on overall clinical outcomes. If our goal is to transform practice, we must build from the bottom up and we must keep in mind how difficult it is to implement anything more in the primary care setting. We must identify those elements of person-centred care that are absolutely critical to its success (not just things ‘it would be good to know’). We must figure out how to efficiently and reliably collect and use information about those elements. Finally, we must find a way to integrate these elements into everyday care. This will be a daunting task, and it will be inextricably linked to advances in health IT. Here is a short list of things we need to do as soon as possible in each area, along with a few examples of work that is currently underway.

Develop a patient-centred ‘primary care data model’

This must be a simple way to portray the information needed for routine primary care practice: the specific data elements, their relationships and how they are to be used in care. The model can also point to the most effective ways to capture and display that data, but capture, display and analysis should be as flexible as possible.
A group of primary care leaders in the USA have produced a first draft of a data model to support the PCMH. The model, presented in Fig. 4, consists of five domains and is intentionally patient-centred. This model moves beyond ‘diagnosis’, including patients’ own expectations, needs and priorities – their reasons for encounter – as integral elements representing the personal context. These elements can be captured with the use of the International Classification of Primary Care.

**Identify and operationalize key domains and data elements of the ‘patient side’**

As investigators, social scientists and patients collaborate to develop the full content of person-centred diagnosis and care, we must agree upon the most important (and recordable) elements, then work to find ways that each can be reliably integrated into everyday primary care work flow. If patient-centred data are not core, they will not become part of care.

**Collaborate with EHR – and PHR – vendors to implement standards**

Once an acceptable data model and core patient-centred data elements are in hand, we will need to work with any willing vendors to develop the capacity to implement them in EHRs and/or personal health records (PHRs) intended for use in primary health care. In some countries, where primary care EHRs have been developed by primary care clinicians or by collaborations between clinicians and IT experts, this may be an easier task than in countries where collaboration is not as well established. Initial efforts have been made in the USA to collaborate with PHR vendors such as Microsoft to develop interoperable software as part of the clinical groupware approach. The goal here is to develop next-generation health IT that is interoperable and fit-for-purpose for patient-centred care.

**Think far beyond the encounter as the unit of health care delivery**

Clinician–patient interactions will increasingly be indirect and asynchronous, through telephone, email, secure electronic portals or other means. Ensuring that the array of health IT applications that will collect patient-centred data are interoperable will require simple standards and robust technology to move information from place to place. We can learn how best to do this from collective experience ranging from the British NHS to small pilot tests of practice-based software.

**Conclusion**

We are intentionally taking the long view here, with the caveat that advances in health information technology may provide new ways to integrate person-centred care: for example, advances in knowledge management may improve our ability to build limited data decision support tools into software. But the work agenda laid out in the previous section should remain fundamentally the same regardless of technological advance.

In the end, the core task of general medical practice is to meet the needs of people living in communities. We must find a way to bring the patient’s own voice into our work.
References


The practice of person-centred medical care requires doctors to examine basic questions about the scope of medical responsibility, the nature of the therapeutic doctor–patient relationship and the types of procedures that are appropriate in treatment and health promotion. Health is defined by the WHO as a state of physical, mental, social and spiritual well-being [1]. Well-being is more than absence of disease; it is a state of being healthy, happy, productively contributing to one’s community and satisfied with one’s life. Health and well-being then include strength and resilience of the body, thoughts and psyche of a person as a whole.

Once well-being is recognized as an integral part of health care, then health promotion must address the whole art and science of living well. However, attention to the art and science of living well does not mean that every aspect of life becomes the full responsibility of a doctor as a controlling authority who fights against anything risky as wrong or disease-promoting. Human beings only flourish when they are self-directed, cooperative and self-transcendent [2]. In other words, mental health has been defined as a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community.’ [1,3] Consequently, it is ineffective to treat a human being as a dependent child who follows submissively the person-centred doctor shares his or her knowledge and expertise with the larger community so that society as a whole can be informed in making decisions about how best to promote health and well-being.

What procedures can the person-centred doctor apply that are practical and effective? First, the doctor needs to know who the person he or she is encountering really is. The doctor must understand the personality of the individual including their emotional style, their goals and values, their strengths and weaknesses physically, mentally, socially and spiritually [4].

Second, there must be a therapeutic alliance in the sense of a relationship of mutual trust and respect in which the doctor and patient agree to work together towards common goals [5].

Third, therapeutic encounters are enhanced by reassurance and calm. Most encounters with doctors involve stress-related complaints and result in rushed encounters and prescriptions with which compliance is poor, creating a cycle that is costly and ineffective. People are often unable to think rationally when they are acutely distressed or in a state of negative emotion, such as anxiety or anger. The emotional brain actually short-circuits the function of rational cognitive processes when a person is distressed [2]. Consequently, doctors need to communicate in a reassuring and hopeful manner. Brief relaxation methods can be taught in a few minutes, and this provides an inexpensive tool for promoting an essential step along the path to well-being. A key check on this step is to ask ‘Are the doctor and patient calm and respectful?’
Fourth, once a person is calm, they can face and accept unpleasant facts, such as information about a possible disease or abnormal test results. Such acceptance of facts is essential for undistorted analysis and reflection on how to proceed with treatment or changes in lifestyle [6]. If the patient is incapacitated or unable to decide for him- or herself, family members or guardians will need to be calmed and informed so that they can rationally understand and consider how to proceed. A key check on this step is to ask ‘Are the doctor and patient empathetic and reflective?’

Fifth, as soon as possible, it is desirable to reflect on what changes in lifestyle would be helpful in promoting health or reducing the burden of disease. It can be empowering for a person to take responsibility and act in ways that are purposeful and resourceful. Such empowerment improves the mental attitude of the person, fosters hope, and these attitudinal shifts augment the benefits of other lifestyle changes, rather than fostering fear and dependency [7]. A key check on this step is to ask ‘Are the doctor and patient genuine and aware of how to promote health?’

According to Carl Rogers, effective person-centred psychotherapy depends largely on three key elements in the therapeutic encounter: (1) respect or unconditional positive regard; (2) empathy; and (3) genuineness [8,9]. These three common factors in psychotherapy also correspond to the three general principles for the development of well-being: (1) Working in the service of others, which fosters trust, mutual respect and hopeful self-directedness; (2) Letting go, which fosters cooperativeness, compassion and empathy; and (3) Awareness, which fosters genuineness or authenticity and leads to health promotion [2]. Likewise, cognitive behaviour therapy, which incorporates these common elements when effective, is beneficial even in patients with marked somatization [10]. However, cognitive behaviour therapy has a high drop-out and relapse rate unless it is integrated with marked somatization [10].

More work is needed but it appears likely that the general conditions for well-being are also the essential ingredients of effective person-centred care in medicine generally. Technical procedures enhanced outcomes only to a modest degree in psychotherapy, but may be of greater importance with specific medical disorders. There is now growing evidence and recognition that all therapy, but may be of greater importance with specific medical procedures enhanced outcomes only to a modest degree in psychotherapy, substantially improving the development of well-being [11]. Certainly then, there is need for combining medical and psychobiological expertise with non-specific common factors in person-centred care. Given how frequent stress-related complaints are in medicine, it is likely that the common factors that account for most of the outcome in psychotherapy and the principles for the development of well-being are also broadly applicable to all person-centred care.

### References

From the Second Geneva Conference on Person Centered Medicine
Person-Centered Medicine: From Concepts to Practice

The Patient-Centred Medical Home in the USA
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Abstract

Rationale  The Patient-Centred Medical Home (PCMH) is a new model of health care delivery in the USA at the primary care level that emphasizes integrated and coordinated care around the patients’ needs and desires. The PCMH emphasizes a practice-wide team approach to provide high quality, accessible and cost-effective health care for acute, chronic and prevention-oriented problems.

Method  This article is a descriptive overview of the PCMH in the USA.

Results  The data on the PCMH have shown decreased mortality, morbidity and increased patient and physician satisfaction with care. Additionally, quality of care and patient access have improved. There has been decreased emergency room utilization, decreased hospitalization and decreased cost per patient.

Conclusion  The PCMH in the USA has been an outstanding transformative model change to re-centre health care back to cost-effective, quality, accessible primary care.

Introduction

The Patient-Centred Medical Home is an idea whose time has come in the USA. Embodied in the concept of the Patient-Centred Medical Home is a new way to deliver health care that is person-centred and is at the epicentre of the transformation of the US health care system. Health care in the USA has become fragmented, uncoordinated and costly. The Patient-Centred Medical Home provides three constructs for health care reform. First, it offers a delivery system reform that places the patient at the centre of the health care system with a primary care team that is doctor-led. Second, it provides a financial construct in which to better pay primary care physicians for the valuable service they provide in integrating and coordinating this care. Thirdly, it provides a political construct in which it visions what a new transformed health care system will look like.

The future of family medicine

The Future of Family Medicine Report [1] called for the development of a strategy to transform and renew the specialty of family medicine to meet the needs of people and society in a changing environment. Without this change in the larger health care system and in the delivery model of practice, it was believed that primary care and family medicine could possibly become non-existent in the next 15 to 20 years [1]. A new model of family medicine was called for. This model would contain 11 features:

1 a personal medical home for patients;
2 patient-centred care;
3 a team approach;
4 elimination of barriers to access;
5 advanced information systems;
6 redesigned offices;
7 a whole-person orientation;
8 care provided within a community context;
9 emphasis on quality and safety;
10 enhanced practice finance, and
11 a commitment to provide a broad scope of family medicine service that was comprehensive.

To help operationalize this newly emerging concept of the Patient-Centred Medical Home, the four primary care disciplines in the USA (the American Academy of Family Physicians, the American College of Physicians, the American Academy of Pediatrics and the American Osteopathic Association) came together in 2007 to create the Joint Principles of the Patient-centred Medical Home [2].

These seven Joint Principles are the following:

1 A personal physician who coordinates all care for patients and leads the team.
2 Physician-directed medical practice with a coordinated team of professionals who work together to care for patients.
3 A whole-person orientation, which is the key to providing comprehensive care.
4 Coordinated care that incorporates all compliments of the complex health care system.

5 Quality and safety in which medical practices voluntarily engage in quality improvement activities to ensure patient safety is always being met.

6 Enhanced access to care (i.e. open access scheduling and communication mechanisms).

7 Fair and balanced payment in which reimbursement is reflective of the true value of coordinated care and innovation.

These seven Joint Principles were not only approved by all four of these primary care organizations, but by the American Medical Association. They have been championed by the Patient Centered Primary Care Collaborative, which is an organization that represents over 750 organizations from big business, to insurance companies, to physician organizations, to consumer groups, to unions [2]. They all have as their purpose to re-centre the US health care system on primary care and the Patient-Centred Medical Home at its epicentre. The true value of the Patient-Centred Medical Home represents both a place of care (as it is a practice that so gets designated) but even more importantly, the Patient-Centred Medical Home represents a process of care, which is long overdue in US health care. This process consists of integration and coordination of care through trusted physician relationships to help the patient navigate the complexity of health care and the US health care system. Acute, chronic and preventive conditions are all dealt with proactively by the team located in the Patient-Centred Medical Home for the good of the patient. These trusted relationships are built on shared responsibility between the physician and the patient so that both are held accountable for quality outcomes.

A new model for medical practice

The Patient-Centred Medical Home is patient-centred and physician-directed. It builds on the core foundation of family medicine and primary care, which has comprehensive, continuous and relationship-based care at its basic level. The Patient-Centred Medical Home then adds on quality measures such as a culture of improvement, performance measurement and reliable systems to collect information in order to provide patients what they need. It then adds the patient experience, which is measured by convenient access, personalized care and care coordination so that patients are more satisfied with their care. It then adds on practice organization in the form of financial management, personnel management and clinical systems so that the practice works efficiently. It then adds on health information technology that consist of business and clinical systems so that the practice works efficiently. It then adds the patient experience, which goes forward to meet the complex health care needs of the US society.

The Patient-Centred Medical Home for the good of the patient. These trusted relationships are built on shared responsibility between the physician and the patient so that both are held accountable for quality outcomes.

In conclusion, the Patient-Centred Medical Home has become a central feature of the US health care system reform. It has met what was called for in the Future of Family Medicine Report as the delivery model reform that was needed. The Patient-Centred Medical Home is an idea whose time has come to re-centre the US health care system on what we are trying to do for patient’s care and for the people of our country. The data support that it is moving our health care system to be more accessible, higher quality, more satisfying and less costly. It is doing so by leveraging relationships and trust in a wellness and preventive approach of getting people to the right care location to be seen by the right physicians at the right time for the right reasons. It is helping people sort out what they need and maybe even more importantly, what they don’t need. The concept of patient centredness will most likely evolve to patient centredness with time and the USA will continue to refine the concepts of the Patient- or Person-Centred Medical Home as it goes forward to meet the complex health care needs of the US citizens in a rapidly changing environment.

References


A personal approach to person-centred paediatric care

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Abstract

Respecting children in their own right as individual ‘persons’ improves their care and their well-being. Better educational progress by each child is achieved. This in turn improves the economic potential for the nation. Each child has physical, mental, emotional, social and spiritual needs. Early attunement between the parent and the child is crucial and an approach that integrates all the elements that affect the child as a person has been found to be effective in promoting positive health outcomes.

Each child is a unique individual who has needs, which include those that are physical, mental, emotional, social and spiritual in the form of ’love’.

The greatest worldwide challenge today remains the health of our children [1]. This determines the social educational and economic growth of all nations [2]. The most cost-effective investment nations can make is to focus on all three elements of health maintenance and disease prevention namely primary, secondary and tertiary prevention [3].

Medical care needs to start with the child and support systems that maintain the integration of all those elements upon which health and well-being are founded. Only the context will differ within different countries.

There is plenty of evidence that such an integrated approach is the most effective health measure [3].

I observed this at first hand in Kerala with the Integrated Child Health Scheme originally supported by the WHO 20 years ago where the promotion of health was partnered with social and educational support in the village community.

UNICEF cause quite a stir with their Report Card 7 from their Innocenti Research Centre in Italy, which gave an overview of Child Wellbeing in a list of 21 ‘rich’ OECD countries with the USA [4]. Six dimensions were analysed from each countries’ own figures for material well-being, health and safety, educational well-being, family and peer relationships, behaviours and risk and subjective well-being. Of the 21 countries the UK came bottom of the table.

Some insight can be found in a study based in Turkey about 30 years ago on the views of 20,000 mothers in nine different countries about the value of their children [5]. Their responses were classified under three headings – utilitarian, social and psychological.

The utilitarian group included those who rated the economic and material benefits arising from children both when they are of child age and when they grow up to be their security in old age.

The social group valued the general social acceptance that normal adults are given when they have children and their desires for the continuation of the family.

The psychological group was those mothers who valued their children as individuals in their own right had fewer children and fewer died.

It is interesting that those values of love joy and companionship are more part of a person’s ‘spirit’ difficult to measure, usually discounted in health care but actually very important.

We need to rediscover the research finding of John Bowlby [6] and others that a child’s first relationship, the one with the mother, acts as a template that permanently moulds the individual’s capacity to enter into all later emotional relationships.
The crucial elements are early attunement or essentially what we understood as ‘bonding’ and the development of empathy [7]. Attunement takes place when the parent and child are emotionally functioning ‘in tune’ with each other and where the emotional needs of love acceptance and security are met. Without satisfactory early attunement to the primary care giver, the development of empathy can be greatly impaired.

Empathy entails the ability to step outside oneself emotionally and be able to suppress temporarily one’s own (selfish) perspective on events to take another’s. It is present when the observed experiences of others come to affect our own thoughts and feelings in a caring fashion. When a parent consistently fails to show any empathy with the child’s expression of particular emotions, the child can drop those emotions from his or her repertoire.

Empathy is also perceived as a prime requirement for a citizen to be of the law-abiding type.

We must also remind ourselves that to the best of current knowledge the sensitive ‘window’ for emotional sensitivity and empathy lies within the first 18 months of life and these skills are shaped by the primary care giver. Our brains greatest capacity to be change or be rewired is in the first 3 years [8].

Daniel Goleman, the author of Emotional intelligence, maintains that empathy builds on self-awareness first and that the more aware we are of our own feelings the more skilled we will be at reading the emotions of others [9].

So we need good parents, good parenting and parent empowerment.

**Children need love and boundaries within which to feel secure**

As children develop their cognitive or general thinking skills there is an expectation that they will start to conform to the morals set within the family and wider society. We can get some insights from the differing perspectives of three psychological theories:

- Freud claims that the quality of relationship the child has with his/her parent/s greatly affects the way the child develops morally.
- The Social Learning theory states that children initially learn how to behave morally through modelling (imitating appropriate adult behaviour).
- Cognitive-developmental theories promoted by Piaget and Kohlberg, claims that a child’s ability to reason morally depend on his/her general thinking abilities.

Dr Robert Coles, a Professor of Psychiatry at Harvard, in his book the Moral Intelligence of Children widens the practical issues in a narrative and discursive way [10]. A child is shaped at the very start of life by the values of certain adults. Even before a boy or girl is born, his or her parents are already giving expression to their values that will matter to their son or daughter. A women tries to think of others, not only of herself, so she watches what she eats and drink and does not smoke not only out of concern for herself but with her future child in mind. A man takes an interest in the woman who is carrying his child offering affection comfort and reassurance. Both parents are concerned for the third person to arrive.

And this leads up to what he describes as a ‘golden rule’ – a respect for others, a commitment of mind heart and soul to one’s family, local community and nation! Moral intelligence isn’t acquired by ‘dictat’ or by the memorization of rules but as a consequence of learning to be with others and taking to heart what we have seen and heard. The child is a witness of ‘grown up morality and looks for clues as to how one ought to behave from parents and teachers making choices, talking to people showing in action our basic assumptions, desires and values and thereby telling these young observers more than we realize.

So these concepts need to be woven into the support we give to families in their children’s journey from infancy through adolescence. We are paying a very heavy price for not doing so [11]. The cost of intervening when everything has broken down is so much more – by a factor of between 10 and 20 times depending on the study. When money is tight, we cannot afford not to help.

Allen and Duncan Smith’s have proposed a system of integrated support based on a ‘virtuous circle from the experience in the city of Nottingham [9]. They suggest a focused continuing theme and scheme of a Prenatal Package. Post Natal Support, Preschool Sure Start Children’s Centres and Primary School follow on programmes, and at Secondary School ante drug and alcohol and pre-parenting skilling.

- Being both socially well adjusted and employed leads to:
  - lower levels of addictive behaviour;
  - lower likelihood of being trapped in poverty and low-quality housing;
  - greater likelihood of having only the number of children people can parent effectively and afford to support without sliding into dependency, and
  - greater likelihood of people being naturally good parents to their own children and thereby feeding into a positive rather than negative generation cycle [12].

This needs underpinning by a ‘spiritual (concepts of love) and moral (what is right or wrong) approach.

In the development of medical care for children all these concepts need to be applied locally at individual and community level starting with the child as a person.

- Primary prevention means reducing the incidence of disorders and diseases. The most effective of which are ensuring adequate nutrition, a comprehensive immunization programme tailored to the local needs, anticipatory guidance of advice and support for parents and children, accident prevention, dental prophylaxis.
- Secondary prevention aims at reducing the prevalence of disease and poor health by early detection and prompt and effective intervention. Awareness and screening are some of the means that early identification can be achieved. The first three criteria of Wilson and Junger’s 1968 WHO criteria for the evaluation of screening programmes are that there should be a potential health gain, and acceptable treatment or intervention and facilities should be available, the latter raising local issues [13].
- Tertiary prevention aims to minimize suffering and reduce impairments and disabilities caused by disease. Many acute and chronic diseases come under this area.

The great advantage on the former Integrated Child Development Scheme in Kerala was that it encompassed all three elements of prevention as well as the acute childhood diseases. The scheme was grown from the local community with a locally trained lead health worker supported by paediatric care. Essential nutrition was included with a full immunization programme, parental guidance and family planning. Each individual child was important; each had their own meticulously kept record. It was starting to have a measurable health impact.
A similar model evolved in the UK at the beginning of the last century in the form of child health clinics, which at their hay day included access to social and educational support through local authority services.

As some of the measurable indices in both ‘cases’ were reduced, the integrated idea was abandoned. It has begun to be resuscitated again many years later in a different primary care context and seems to be gaining favour with the WHO again with their initiatives on people-centred medicine [14].

References

Person-centred medicine for older people

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Abstract

It can be argued that person-centred medicine is more important in old age than it is in young or middle age. The older patient is in many respects more of an individual than he was in his younger age as life experiences including diseases have shaped each person for a long time. For evaluation of an older person, the team approach has been shown to be the most efficient method. Cognitive factors and social support must be addressed specifically.
patient futile. Cognitive decline that is not severe enough to merit the term dementia often goes undetected but is nevertheless important. Those treating the patient need therefore to evaluate cognition and more precisely, to what degree cognition has deteriorated and how. To evaluate the psychological health of the patient is also of utmost importance. Older persons often tend to explain their symptoms by their chronological age and that makes their contribution to their own treatment suboptimal. Depressive symptoms and overt clinical depression are of course great obstacles to treatment success as well. The time used to evaluate a person’s cognition and to communicate with him is therefore time well spent. The social support is also of utmost importance for his possibilities for independent living. For evaluation of social status and support it is necessary to involve others such as family members and the persons responsible for the social service in the community. Before doing that the patients’ wishes must be respected. He knows best to whom he wants to turn for help and he might trust some and mistrust others. According to human rights charters such as the Declaration of Lisbon on the Rights of Patients [2], he has the right to know everything regarding his illness, treatment and prognosis, to decide to what extent he is treated and supported and whom to consult in his family or community. The personal preferences of the patient must therefore be respected; in other words, the personal-centred approach to treatment must guide the work.

The demented person is a special challenge in the person-centred perspective. Is it possible to communicate with the person behind dementia and to learn about his priorities? The answer to this question is yes, if it’s done early enough in the disease process. This means that in the first phase of dementia the treatment team must address those issues with the patient that might have relevance in the coming years. In his pioneer work, Kitwood presented the term personhood in the context of dementia [3]. Until then, most of the work in this field had focused on medical and psychiatric symptoms of the patient and how to respond to those. The patient was identified by his symptoms and the evaluation was directed on those and their relevance to the patient and to his immediate environment. Little or no attempt was made to communicate with the person as such and to come to terms with his thoughts and wishes. Little attention was given to the fact, as most agree to today, that most of the psychiatric symptoms in dementia originate from a person’s coping strategy in a bizarre situation. By understanding the situation of the patient, much more could be achieved than by just looking at the disease symptoms per se [4]. This in turn has shown to reduce the usage of drugs for the psychiatric symptoms, to increase the well-being of the patient and to increase work satisfaction of the staff [5]. These ideas are behind many projects in dementia care such as the VIPS concept and many others [6]. This has not been an easy road as dementia care has not been highly regarded by clinicians and problems such as high personal turnover in the care setting is prevalent. It can therefore be argued that dementia care, when it is done in the spirit of Kitwood, is one of the best examples of person-centred medicine, of the person, for the person and with the person [7].

References
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Person-Centered Medicine: From Concepts to Practice

The value of tailored communication for person-centred outcomes

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Keywords
adherence, communication, outcomes, recall, tailored

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Abstract
Rationale When entering a consulting room a person becomes a patient with double needs, that is, the need to feel known and understood and the need to know and understand, also referred to as affective and instrumental needs, respectively. The fulfillment of these needs highly depends on the communication skills of both doctor and patient, which help to bridge the inherent distance that exists between these two persons. There is ample evidence that this bridge becomes stronger the more the communication is tailored to the person behind the patient. Besides, such tailored communication may also prove to be effective for reaching favourable health outcomes.

Methods Descriptive study focusing on the value of tailored communication in promoting person-centred instrumental and affective health outcomes.

Results Research shows that tailored communication contributes to health outcomes known to be crucial for recovery and quality of life, that is, information recall, medication adherence, reassurance and need fulfilment.

Conclusion There is empirical evidence for the value of tailored communication for person-centred outcomes. Communicating in a purposeful way while at the same time respecting patients’ values and feelings should therefore become the standard in health care practice.

Introduction
When seeking health care a person becomes a patient with double needs, that is, the need to feel known and understood and the need to know and understand, also referred to as an affective and an instrumental need, respectively [1,2]. The fulfillment of these needs highly depends on the communication skills of both doctor and patient; a doctor’s adequate, patient-centred communication style contributes to signal and identify a patient’s needs. Likewise, a patient’s open and clear presentation of his reason for visit adds to an effective and efficient encounter by which a patient feels helped, empowered and cared for. Clearly, both doctor and patient can be held responsible for the process and outcome of a health care. By recognizing each other’s valuable role and input, the doctor and the patient together help to bridge the inherent distance that exists between them. There is ample evidence that the doctor–patient bridge becomes stronger the more the doctor’s communication is adapted to the person behind the patient, that is, to the person with his idiosyncratic way of reasoning, understanding, feeling and behaving. As a consequence of the differences in background and expertise, patient’s perspectives often clash with the perspectives of the doctor [3]. Interpersonal communication, which takes into account these differences in life world and personal circumstances as well as the patient’s individual level of comprehension, coping skills, informational needs and emotional needs, increases the chance of being heard and of reaching desired health outcomes. Such a patient-centred approach can therefore be understood as being prerequisite for tailored communication. According to Kreuter et al. [4] tailored information is intended to reach one specific person and is based on individual characteristics related to the outcome of interest, derived from an individual assessment. Individually tailored information is often confused with targeted or personalized messages. An intervention is targeted when it is intended to reach some specific subgroup of the general population, usually based on one or more demographic characteristics shared by its members. Information is considered personalized when it is adjusted only to population-based demographic data, for example, the respondent’s name [4]. On the basis of the Elaboration Likelihood Model [5], tailored messages can be expected to yield more favourable health outcomes. Making a message more personally relevant by tailoring, stimulates motivation for thoughtful consideration, which leads to more stable attitudes [6]. This is supported by EEG research showing that tailored information increases attention rates [7]. The present short paper aims to
provide examples of recent empirical studies underlining the value of tailored communication for specific person-centred health outcomes.

Methods

Descriptive study focusing on the value of tailored communication in promoting person-centred instrumental and affective health outcomes known to be crucial for recovery and quality of life, that is, increased information recall, medication adherence, need fulfilment and reassurance.

Outcomes of tailored communication

Research suggests that tailored communication influences person-related outcome in the following ways.

Information recall

Doctors often need to provide large amounts of information. Research in patient education about chemotherapy shows that oncology patients receive information and advice about 32 different topics [8]. These patients appear to be able to recall less than one quarter of these advices correctly [8]. As a consequence, many oncology patients do not know how to cope with the severe side effects of the treatment that need immediate medical attention and health professionals spend a lot of time without achieving their goal of educating and empowering patients to become responsible for their well-being. Fortunately, it appears possible to teach health professionals how to provide information in a more person-centred and tailored way by restricting the amount of information to the main topics and by providing more detailed information only about the topics that patients indicate to be of value to them [9].

Medication adherence

Many patients do not use their medication as prescribed. An often reported reason is that they lack the knowledge about the necessity and fear side effects [10]. A recent observation study in general practice patients with depression, hypertension and asthma/chronic obstructive pulmonary diseases shows that doctors discuss (non-)adherence in only 20% of their visits [11]. To increase adherence, an open and honest talk about what hinders and facilitates proper use is needed. To this purpose, a person-centred approach is crucial because an adherent patient may have become non-adherent the next day and reasons for non-adherence differ between patients [12]. To find out if a patient has difficulties taking medication, a person-centred doctor shows interest, listens carefully, takes the patient seriously and asks goal-directed questions in an environment without any shame and guilt. This is expected to yield up to a 19% decrease in non-adherence [13,14].

Need fulfilment

Overall, doctors are quite good in fulfilling patients’ needs [15]. Still, talking about psychosocial issues seems difficult. Familiarity between a doctor and a patient – a proxy measure for personal continuity – is expected to ‘open up the communication’ for more psychological and social topics [16]. However, research shows that familiarity – applied in 394 general practice visits – does not influence the content of the communication in terms of medical issues, psychological themes or topics relating to the social environment. Doctors should therefore be aware of the pitfall that being acquainted with a patient for a long time does not automatically guarantee person-centred communication or correct perceptions of a patient’s informational and affective needs. For clinical practice this implies that exploring cues and checking mutual understanding remain crucial even in long-established doctor-patient relationships.

Reassurance

Positive communication between a doctor and a patient might influence patient outcomes, especially in patients with minor ailments. Research analysing 524 general practice visits indeed shows that reassurance is related to patients’ better overall health [17]. In addition, this study also shows that providing a favourable prognosis is linked to patients feeling better and giving a clear explanation is related to patients feeling better and less anxious. However, these relationships disappear when patients report a low mood pre-visit. This suggests that a doctor should be keen on exploring a patient’s emotional well-being. This is no simple task, because an observational study in 97 everyday general practice visits indicates that many patients only express their emotional concerns in an implicit way [18] and doctors explore patients’ emotional cues most often in a medical way only [19]. Doctor-patient communication is likely to become more person-centred by being conscious of a patient’s implicit way of communication and by exerting self-reflection on one’s one-sided medical approaches.

Conclusion

Person-centred communication asks from a health care professional to be alert on:
- Changing circumstances. Also if a patient has known a health care professional for a long time, circumstances may change resulting in more unhealthy behaviour in your patients, such as medication non-adherence.
- Too much information. Many patients can only recall part of what you tell them, so you better restrict the amount of information to what patients need to know and want to know.
- Hidden emotional cues. Many cues are being missed while research indicates that negative emotions may hinder a patient to feel reassured and to trust in a positive outcome. This makes it highly relevant to watch out for emotional distress in your patients.

References


Research on person-centred clinical care

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Abstract

Rationale, aims and objectives  To give a selective review of empirical studies on person-centred clinical care, in particular concerning communication patterns between patients and providers.

Methods  Descriptive and selective review of relevant literature.

Results  Person-centred clinical care may have positive effects on patient satisfaction, patient adherence, health care utilization, malpractice litigation and health outcome.

Person-centred communication skills may be promoted by way of communication skills training.

Conclusion  The concept of person-centred care is rare in the empirical literature. Future research should operationalize the concept and design studies of the impact of patient-centred clinical care.

Introduction

Person-centred clinical care and medicine of – or for – the person are concepts applied to highlight a novel emphasis on the whole person in medicine, in contrast to a limited focus on disease mechanisms and fragmented health care practices [1,2]. But in the empirical literature on provider–patient communication and other aspects of clinical care, there are few explicit references to these concepts. There are, however, a number of other, and in some sense similar, terms that have been applied to characterize person-centred aspects of clinical care such as patient-centred medicine [3,4], narrative medicine [5] and relationship-centred medicine [6].

The most common concept of these in the research literature on provider patient communication is probably patient-centred. The concept of person-centred is wider than patient-centred. Person-centredness concerns not only the patient, but includes in a sense also the provider who is also a person. In that sense, it is similar to the concept ‘relationship-centred’. A person-centred understanding of medicine looks at the patient as a whole person, not restricted to the role of patient, and opens up a room of reflection on the values of medicine.

Because the concept of person-centred medicine seldom is applied in actual research on clinical care, we will have to look for other concepts relevant to person-centred medicine, such as patient-centred communication [3], health provider exploration of patients’ cues and concerns [7], empathic responses to emotional needs [8], the ability to establish common ground and a trust relationship [9], and a positive approach emphasizing personal resources, coping strategies and health promotion [10]. In this paper we will briefly and somewhat selectively review studies on some of these qualities of care, in most cases limited to the study of communication patterns between patients and providers, most often doctors.

Person-centred aspects and outcome measures

A number of studies have documented significant associations between some of these aspects of person-centred clinical care and different outcome variables, such as patient satisfaction, patient adherence, health care utilization, malpractice litigation and health outcome.

Patient satisfaction is by far the type of outcome which is most heavily researched in the clinical communication literature. Quite consistently length of consultation is related to outcome; the longer the consultation, the more satisfied the patient [11]. Within reasonable limits provision of time for the patient may be considered a person-centred quality of care.

Both task-oriented and patient-oriented aspects of communication are related to satisfaction. Among the more patient-centred qualities of care most consistently related to satisfaction are a non-dominant communication style and much information giving [11].

Patient adherence seems to be a more complex phenomenon than patient satisfaction. Research indicates that adherence
depends more on the patient’s medical condition and other specific factors. The most well-documented effects on adherence are found in studies of technical solutions (simplification of dosage, etc.), reminders and incentives [12]. However, some aspects of provider communication behaviour that represent person-centred approach to care have also been found to promote adherence, such as adequate information provision, provider empathy [13] and a trusting provider-patient relationship [9].

There are fewer studies on the impact of communication on health care utilization. There are some indications that person-centred communication may reduce the number of consultations and days in hospital, and be associated with continuity of care. In one study, a lack of trust in the doctor was a good predictor of disenrollment from primary care doctors’ practice, underscoring the importance of a trusting doctor–patient relationship [9]. A recent review addressed communication behaviours that were associated with efficiency in medical consultations. The researchers found that both rapport building and the acknowledgement of social and emotional cues, both examples of person-centred skills, were positively associated with communication efficiency [14]. Moreover, there is good documentation that a person-centred communication style may protect against complaints and litigation claims form patients [15].

An important area of research is the effect of communication style on health outcomes such as symptom resolution. There are relatively few studies in this area (for review, see [16]). Among the studies that exist, there is evidence that doctor–patient interaction patterns may be related to a number of outcome indicators, even physiological markers such as blood sugar levels and blood pressure [17]. The research literature on placebo effects has documented mechanisms that may explain how communication behaviour may affect health outcome [18].

Communication skills training

Another line of studies is the research on the effect of communication skills training. Although results are mixed, a number of studies indicate that a person-centred approach to clinical care may be learned, and that the skills acquired by health care providers after communication skills training may impact patient outcome. A recent review concluded that a number of provider skills, which may be characterized as person-centred were enhanced after communication skills training, such as eliciting patient concerns, exploring the impact of the illness on patient’s life and expressing empathy [19].

Many interventions include course content which explicitly emphasizes person-centred care, such as the so-called Four Habits Approach, developed in the USA within the Kaiser Permanente system by Richard M Frankel, Terry Stein and others [20]. One of the habits is to elicit the patient’s perspective in the consultation, a skill often neglected in many consultations [21]. Another person-centred habit is to demonstrate empathy. The two other habits are to invest in the beginning and the end, respectively, of the consultation. The programme illustrates the emphasis on person-centredness in communication skills training programmes.

Conclusions

Because the concept of person-centred is rare in the empirical literature, caution should be displayed in drawing conclusions. However, there are indications that a person-centred clinical care is positively related to patient satisfaction, may have a positive effect on adherence and adequate health care utilization, seems to protect against patient complaints and litigation claims, and may have direct positive effects on a number of health outcomes. Moreover, person-centred practices may be promoted by way of communication skills training. Future research should be guided by efforts to operationalize the concept of person-centred medicine more explicitly and to design studies of the impact of person-centredness on clinical care.

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