

EDITORIAL INTRODUCTION

The chronic illness problem. The person-centered solution

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Introduction

On 8 December 2015, the World Health Organization (WHO) published its comprehensive analysis of global health trends: 'Health in 2015: from MDGs to SDGs' [1]. The analysis, in providing a 15-year retrospective to the Year 2000, also looks forward prospectively over the same interval in an effort to present an assessment of the challenges to global public health and sustainable development up to and including the Year 2030. The Report is clear that existing and emerging communicable diseases are, as we move forward through 2016 and into the next decade, a formidable challenge for governments and their health systems. Key drivers of progress in health under the United Nations Millennium Development Goals (MDGs) are identified, along with a variety of actions to which individual countries and the international community more broadly should afford prioritization if the new (and highly ambitious) sustainable development goals (SDGs) are to be achieved. The associated WHO Strategy set out within the Report entered into operational force on 1 January 2016 [1].

The threats posed by the communicable diseases are therefore grave, but a major additional consideration for global public health has emerged over recent decades - a dramatic rise in the incidence and prevalence of long term, chronic co- and multi-morbid illnesses. The WHO recognizes this additional challenge (having in 2005 defined chronic conditions as those which require "ongoing management over a period of years or decades" [2]), publishing its first substantive analysis on the non-communicable diseases (perhaps somewhat belatedly) in 2011 [3]. Two further major reports followed in 2014 [4,5]. All three NCD reports agree on the appropriateness of a formal revision of the definition of the NCD

phenomenon from pandemic to *epidemic*. Indeed, of the 38 million deaths annually attributable to NCDs, over 14 million such deaths occur in people aged between 30 and 70 and thus during the most productive years of life. Moreover, the morbidity and mortality resulting from these illnesses is not simply a Western phenomenon, but continues to increase in low and middle income countries in parallel [1-5].

The 2014 WHO Reports [4,5] concentrate explicitly on cardiovascular disease, the cancers, diabetes [cf. 6], chronic respiratory diseases and on the risk factors that predispose to the development of these conditions either as primary pathologies or, increasingly, co-morbid conditions. To be sure, the mortality statistics recorded by the WHO (likely underestimates given data provision limitations) are sobering indeed and it is no surprise to see the focus of the WHO on largely preventable, high volume diseases in accordance with the fundamental remit of that organization. But for every high volume and potentially preventable disease identified by the WHO, there is another disease, perhaps not so high volume and perhaps not at all so potentially preventable, that is associated with equal, if not greater, human distress and suffering. In this context we refer to the common neurodegenerative diseases, to other long term conditions which remain communicable such as HIV/AIDS and HIV-HCV co-infection and to a plethora of other examples including musculoskeletal, joint and dermatological conditions and a wide range of specific conditions which precipitate major reductions in patient quality of life. Even taking all of these fully into account, we cannot forget the medically unexplained illnesses and also the so called 'rare diseases'. And what of the worldwide epidemic of chronic mental health illnesses and the dementias in addition? And what

of those patients who live with physical impairments and those who experience intellectual disability?

If we are to talk about the current state of global health and disease - and how to improve it - then in attending to the care and empowerment of the individual patients who collectively constitute the epidemiological populations with which the WHO is so very rightly concerned, we must *also* look beyond them. Indeed, there is a risk that the so-called 'high profile' diseases can occupy too prominent a place on the international public health stage, to the detriment of the other conditions to which we refer, with the latter being essentially 'forgotten' as a function of their relegation to a second or third order of relative importance.

In this *Editorial Introduction*, within the confines of available space, we will consider the vital role of person-centered healthcare (PCH) approaches in enabling individual clinicians, clinical teams and healthcare systems to assist and accompany patients and their families along their chronic illness trajectories, whether these illnesses are 'high profile', 'high volume', 'potentially preventable' - or not.

The person-centered care of chronic, long term co- and multi-morbid illnesses

The chronic, long term co- and multi-morbid illnesses, indeed all those conditions that can be pragmatically classified as such under so broad and convenient a descriptor, continue to exact a major toll on human health and suffering and greatly diminish the capacity of affected individuals to flourish and live well. The economic effects of these conditions are as serious as their clinical consequences and have the potential, collectively, to bankrupt health systems worldwide [2-5]. One pre-eminent characteristic of the chronic illnesses is their ability to cause, in addition to their somatic effects, profound psychological morbidity and emotional, spiritual and existential distress - and not only to patients. Indeed, the nature of these diseases is such that their effects do not remain confined to the affected individual, but rather radiate outwards to families and friends and to Society at large in terms of their fiscal and social impacts. It stands to reason, therefore, that any approach to care that could be considered remotely adequate would attend not simply to the modification of biological disease using medicine's scientific knowledge, but would address the broader needs and requirements of the person as a whole [7-11]. Indeed, these patients present for assistance not as a collection of organ systems, one or more of which may be dysfunctional requiring scientifically indicated technical and pharmacological interventions, but rather as integral human beings with narratives, values, preferences, psychology and emotionality, cultural situation, spiritual and existential concerns, possible difficulties with sexual, relational, social and work functioning, possible alcohol and substance abuses and addictions, worries, anxieties, fears, hopes and ambitions - and more [cf. 12].

While it is a *sine qua non* that the diagnosis and treatment of primary biological pathology(ies) remains central to the amelioration/attenuation of somatic disease, it is essential to remember that in the context of chronic illness this is *simply the beginning* of a long process of accompanying the patient and his/her significant others along a typically extended duration of illness. Here, the old formula of 'diagnose, treat, cure, discharge' is *ipso facto* inapplicable and newer, more 'fit for purpose' models of care have become urgently necessary. Thus, when the indicated pharmacological and technical interventions have been instituted, it cannot realistically be concluded that this is all there is to do and that all of the other manifestations of the illness are somehow 'someone else's concern' and not that of the attending clinicians. Such a 'model' of care would be a failure, rich in technical skill and poor in humanity, raising significant concerns about the nature of clinical professionalism as well as begging a range of ethical questions [12]. Clearly, it would be impossible, given current resource constraints, particularly of time, for busy clinicians to attend personally to each and every secondary manifestation of the primary disease(s), some examples of which we refer to above. But within the context of multidisciplinary teams in particular, it becomes more than possible to enquire about any difficulties that are not immediately clinically observable but which the patient may nevertheless be experiencing, then to arrange, *via* the healthcare system, appropriate management through appropriate referrals and to elicit and listen carefully to subsequent feedback from the patient.

Achieving PCH within the 'jungle' of modern healthcare systems - on the need for national 'joined up' strategies and national directors for person-centered healthcare

Achieving the person-centered care of chronic illness in practice will require the coordinated action of a variety of stakeholders, including politicians, policymakers, researchers and educators, multidisciplinary clinical teams, social services professionals, family carers, professional carers, chaplains, NHS managers and transformational leaders, patient advocacy groups, media professionals and the pharmaceutical and healthcare technology industries [cf. 10,13,14]. These stakeholders, acting together in accordance with a joined up National Strategy aimed at increasing public awareness of the value of person-centered care, the education of clinical professionals (at both undergraduate and postgraduate levels) and the development of new services and the reconfiguration of existing ones, has the very real potential to drive important and long overdue changes in the way clinical services are delivered to people living with long term chronic illnesses. Through such an approach it becomes possible to respond to the human dimensions of the patient's subjective experience of chronic illness in integration with the

necessary biomedical and technological interventions [15,16]. Such a National Strategy (in whichever country which seeks to write, agree and implement it) will require a National Director for Person-Centered Healthcare, so that political imperatives and expediencies articulated 'top down' can meet local and regional clinical/service concerns articulated 'bottom up'. We set out our thinking on this matter in greater detail within a forthcoming major textbook of the European Society for Person Centered Healthcare [17].

Patient and Public Involvement/Engagement (PPI/E) in Healthcare - a prerequisite for the development of more person-centered healthcare services

Before concluding, we consider a key prerequisite for the development and delivery of more person-centered healthcare services: a far more active involvement/engagement of patients and the public more generally in the conceptualization and planning of healthcare services and in their implementation, evaluation and ongoing refinement. It is clearly preferable to introduce key elements of person-centeredness into new clinical services at the conceptual and design stage, rather than to seek to modify them in this way subsequent to their introduction (though modification of existing services towards a PCH model, though more complex, remains eminently achievable). Yet while patient and public involvement/engagement (PPI/E) is a cornerstone of healthcare policymaking in many countries, it remains significantly underdeveloped in most and for a variety of specific reasons.

An ongoing difficulty with PPI/E and thus its potential to increase the person-centeredness of clinical services remains the matter of definitional clarity. Indeed, a universally agreed definition of PPI/E remains (as for PCH) elusive, although Gallivan *et al.* [18] have recently published a useful categorization of PPI/E activities and their related definitions using a scope-defining study employing a mixed methods approach. Moreover, an Evidence Search by the UK National Institute of Health and Clinical Excellence (NICE) [19] catalogues some 6048 studies, worldwide, of PPI/E, representing a further useful source of clarification of activities and definitions.

A further deficit in current PPI/E initiatives may be seen to derive from a certain reductionist perspective. Recently, for example, Ocloo and Matthews [20], using a selective narrative literature research, concluded that current models of PPI/E are too narrow and that few organizations tended to mention empowerment or address equality and diversity in their involvement strategies. The authors called for greater attention to be paid to such matters as well as to the adoption of models and frameworks that enable power and decision-making to be shared more equitably with patients and the public in the

design, planning and co-production of healthcare. Staley [21] highlights other, yet related, concerns and talks of the complex nature of patient and public involvement in research, given that PPI/E in research is not a single activity, but rather one which takes many forms and which operates at many different levels - strategic and operational, national and local, so that the impact of involvement is highly context dependent.

Progress with PPI/E has been slower than anticipated and at times has appeared tentative and tokenistic. Nevertheless, it remains a key imperative within most Western health systems and the UK NHS, for example, is committed to the progressive implementation of PPI/E as set out in key documents such as 'Transforming Participation in Health and Care' [22]. Given the clear interface between the strategic intentions of current models of PPI/E and those of PCH, there is, we contend, a need to bring these two areas of currently separate study into much closer co-working. The natural inter-relationship between PPI/E and PCH is underexplored and merits much closer examination as part of national strategies for the development and operational implementation of more person-centered healthcare services, such as those national strategies to which we have already referred above.

Conclusion

It has become clear, particularly over the last decade, that current healthcare services for the management of the long term co- and multi-morbid illnesses are not fit for purpose and that they are unsustainable in both economic and person-centered terms. As a consequence, there is a pressing need to move away from our currently impersonal, fragmented and decontextualized approaches to the management of these conditions, towards newer models of care that are personalized, integrated and contextualized. In this way, we can ensure that affordable biomedical and technological advances can continue to be delivered to patients, on the basis of objective clinical assessment, but within a humanistic framework of care which strives to understand the patient's subjective experience of illness and then to respond to his or her very human needs.

Person-centered healthcare is the most compassionate as well as the most scientific model of care currently conceived and represents a high ethical ideal. On this basis it is intuitively the 'right' approach to the management of chronic illness [11]. There is, however, a great deal more than intuition to be taken into account when considering the utility of PCH as a superior model of care above 'care as usual'. Indeed, a rapidly growing empirical research base indicates that PCH is associated with increased patient adherence to both simple and complex medication regimens, that it decreases the frequency of primary and secondary care clinical consultations, that it decreases the frequency of disease and illness exacerbations, that it decreases hospitalization rates and length of hospital stay, that it results in increased patient and clinician satisfaction rates and is negatively correlated with clinician burn out

rates and that it acts to reduce malpractice claims [10,17]. An urgent priority for PCH is to confirm the results of these initial quantitative and qualitative studies, in order to consolidate its evidence-base as the preferred model of choice for responding to chronic diseases and their sequelae. Economic studies of PCH are now necessary in order to illustrate how PCH-mediated changes in service utilization and delivery have the very real potential to reduce or at least contain health and social care costs.

PCH would very wrongly be considered an existential threat to clinical professionalism or as an irritating distraction from the day to day duties of applying biomedical/technical 'care as usual'. In reality, it offers an important opportunity to return to the professions an ambition to treat patients as persons, so that the clinical 'gaze' can be greatly widened and so that the *touch* of the clinician can extend beyond simple clinical examination into something much greater, something altogether far more complete. To move PCH into operational practice within modern healthcare systems it will be necessary to work towards the design and operational implementation of joined up national strategies coordinated by individuals with the capacity to bring all of the indispensable stakeholders into close and functional collaboration. These we have termed 'national directors of person-centered healthcare'. We contend that the agreement of such national strategies and the appointment of such executors should be a priority for governments and we call, at the European Society for Person Centered Healthcare [23], for serious attention to be devoted to such a proposal not only in the UK NHS, but across European health systems (and elsewhere) in general.

Conflicts of Interest

The authors declare no conflicts of interest.

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