

EDITORIAL INTRODUCTION

Person-Centered Healthcare - moving from rhetoric to methods, through implementation to outcomes

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Introduction

For too long, clinicians have controlled, even dictated, the terms of the consultation. Structured questioning, through invitations simply to affirm or deny the presence of specific symptoms, with a failure to encourage the patient to speak on terms that are his or her own [1-3], have precluded a relationship of equals within the consultation - and with entirely predictable results. An increasing distrust, dissatisfaction and a growing determination to share in clinical decision-making have, over recent decades, caused a former passivity to disappear, with the patient's voice having now acquired potent political force [4,5]. This voice is heard not simply at the level of individual 'expert patients', but also collectively through the plethora of effective lobbying organisations, national and supranational patient empowerment organisations and *via* disease-focussed charities. As a function of such influence and advocacy, patients have become progressively involved in their own care planning and many contribute prominently to clinical services reconfiguration and *de novo* service planning as part of patient and public involvement activities [5-11]. Patients now advise both local and national governments and also the pharmaceutical and healthcare technology Industries - in the latter case becoming increasingly involved in clinical trial design and in medicines development itself [12-16].

The scale of patient involvement within modern healthcare systems is historically unprecedented and, by its nature, confronts the clinical professions, governments, policymakers and the healthcare Industry, with unique challenges. This rise in 'patients as sovereign consumers of

healthcare services' has by no means been welcomed by all and there are legitimate concerns for the implications of the new dynamic on the symmetry of the clinician-patient relationship and the characteristics of future healthcare services delivery [17-26]. While patients continue to be exercised by problems in the *efficiency* of clinical services, such as access and waiting times, one recurring complaint relates more to *quality* than quantity. Here, a profound disappointment, even anger, with medicine's ongoing depersonalisation, is now routinely observable, with clarion calls being issued ever more frequently for an urgent correction of such central failings. The resulting demands for more person-centered healthcare (PCH) require navigation, not circumvention, yet an ongoing operational preoccupation with factory style healthcare delivery, as a function of efficiency targets, continues to relegate patients' concerns on the intrinsic quality of healthcare to a secondary order of importance. Attempts to marginalise or ignore the patient's voice in its highlighting of the deficits in care, compassion and general lack of responsiveness within modern health services, are no longer sustainable. Indeed, the argument that person-centered care is an imperative, not an option, possibly constituting a human right, is gaining increasing traction [27-31].

In this Editorial Introduction to the opening issue of the fifth volume of the *European Journal for Person Centered Healthcare*, we briefly consider the 'Why?' and 'How?' questions which dominate the current PCH debate and describe in outline how the European Society for Person Centered Healthcare (ESPCH) is addressing such questions as part of the implementation of its 10 Year Strategic Plan (2014 - 2023). We conclude by emphasising the need to

move, with vision and determination, and through carefully considered yet pragmatic means, from rhetoric to methods, through implementation to outcomes.

PCH - 'Why?' and 'How?'

Two broad questions dominate the person-centered healthcare debate. The first is 'Why?' And the second is 'How?' Of these, the first has been answered in significant measure, but the second has yet to benefit from systematic enquiry.

Why?

There are three principal justifications to 'do' PCH: (a) an ethical/professional justification, (b) a scientific/evidence-based justification and (c) an economic justification.

The ethical/professional justification

Exponential increases in biomedical and technological advances over the last 100 years have radically transformed the scope, possibility and power of clinical practice, driving major improvements in individual and population health. Yet as medicine has become increasingly scientific, it has also become increasingly depersonalised - a trend observed as early as 1927 by Peabody [32,33], later by others [34-36] and which resulted, in the 1980s, in the consolidation of the North American patient-centered medicine movement. Noting an accelerating dissociation of medicine's duty to ameliorate, attenuate and cure, from its duty *also* to care, comfort and console, the founders of this movement highlighted a growing distortion in the ethos of medicine, employing their prefix as a means of indicating a need to reground medicine within its humanistic framework by placing the patient at the epicentre of all clinical endeavour [37-40].

While the patient-centered medicine movement achieved an early impact among many groups of clinicians, it has failed to refocus the clinical gaze of the wider, worldwide medical community, despite almost 50 years of activity. As a consequence, medicine, as we see it practised in 2017, continues to demonstrate a preferential fascination with the molecular and cellular basis of disease, rather than an authentic fascination with the person of the patient. But the disease is part of the patient and not the patient part of the disease, necessitating an approach to assessment and treatment that is as concerned with the patient's subjective experience of illness as it is with objective clinical and laboratory examination. Indeed, 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, spiritual and existential concerns, a cultural situation, possible difficulties with sexual, relational, social and work functioning, possible alcohol and substance abuses and addictions, worries, anxieties, fears, hopes,

goals and ambitions - and more [28]. As persons, patients exist not in isolation, but in relationship and community, therefore requiring not simply an analysis of their genomics, proteomics, pharmacogenomics, metabolomics and epigenomics, but a proper understanding also of their social situation and the extent to which this mediates an adequate, good or poor response to biological and related interventions [41,42].

Such 'patient factors' were infrequently the subject of immediate clinical concern when the epidemiology of disease required of medicine a focus on acute, single diagnosis conditions. But the recent emergence of the long term co- and multi-morbid, socially complex illnesses, which have grown in incidence and prevalence from the status of pandemic to that of *epidemic*, accounting for approximately 70% of global morbidity and mortality, presents an altogether different challenge to modern healthcare systems [43-47]. These complex presentations require complex responses of a nature which cannot be addressed by the classical formula of 'diagnose, treat, cure, discharge' and a continued focus on individual organ systems, and not on the needs of the whole person, has driven an extent of super-specialization and silo-ization that has greatly fragmented clinical services and rendered them unable to serve such patients well. This, coupled with an ineffective functioning of the health and social care interface in many countries, with an absence of new, more 'fit for purpose' clinical methods to deal with the chronic illnesses in a properly holistic manner, risks an essential *abandonment* of the patient to his or her dilemmas at a time when it is *accompaniment* that is instead vitally necessary [48-50].

A neglect of the duty to understand and respond to the patient's subjective experience of illness and the plethora of important needs which derive from it has, over recent decades, seen clinicians function more in the manner of technicians in applied bioscience, delivering modalities dictated by algorithmic guidance and commissioner/reimbursement-dictated protocols, rather than acting as caring professionals exercising skill and judgement in the context of the unique individual case [51]. Leading commentators, reflecting on the same, have lamented the loss of doctors' abilities to care for their patients as integral human beings, warning that a continued depersonalisation of clinical practice risks an essential "failure" of healthcare provision [52] and a maintenance of patients' complaints that they are treated not as persons, but rather 'dealt with' as subjects, objects or complex biological machines [28,42,48].

PCH has been advanced as an essential corrective to the problem of continuing depersonalisation within healthcare, representing a dynamic system that ensures that accumulating advances in biomedicine and technology are delivered to patients within, *not outside of*, a properly humanistic framework of care. In doing so, PCH seeks to elevate current modes of practice to an altogether higher order of skill, replacing basic legal competence with the clinical excellence to which all clinicians should rightly aspire. The need to re-sensitize modern medicine and healthcare to the humanity required of the clinical encounter and thus to return to clinicians and healthcare

systems an *ambition* to treat patients as persons, illustrates the basis of the ethical/professional justification for 'doing' PCH [28].

The scientific/evidence-based justification

On the basis of the ethical/professional justification, PCH can easily be seen to represent the most compassionate and intuitively 'right' way to practise clinically. But there is a great deal more than intuition to be taken into account when considering the utility of PCH within modern healthcare systems.

Over many decades, a substantial quantity of qualitative research has been devoted to exploring patients' views on and satisfaction with PCH-type approaches to care delivery and, in recent years, a rapidly accumulating empirical research base continues to add to this substantial corpus of qualitative data. These two modes of enquiry are collectively demonstrating the ability of PCH to modify a series of important clinical and operational indices with the potential to generate improved clinical outcomes above 'care as usual'. For example, PCH approaches to care are associated with increased patient adherence to both simple and complex medication regimens. They decrease the frequency of primary and secondary care clinical consultations and reduce the frequency of disease and illness exacerbations that often lead to increased hospitalization rates and, on hospitalization, extended lengths of stay. They increase health literacy and the patient's understanding of illness and are associated with the selection of more conservative than radical treatment approaches. They enhance the patient experience and either maintain or increase patient and clinician satisfaction rates with care. They increase the rates of patient self-help and management and either maintain or increase health-related quality of life. They are negatively correlated with clinician burn out rates and reduce malpractice claims [53-61].

These important changes in patient behaviour and service utilization, mediated by the PCH approach, are of major significance to the efficiency and effectiveness of clinical care and health services provision, to the extent that it is no longer possible to ignore the modern utility of PCH in assisting patients to deal with their unique individual circumstances. Nevertheless, additional proof of concept studies are required to augment the current evidence base through further well designed and properly funded health services research (HSR) programmes. When considered together, the qualitative evidence and quantitative empirical research base constitute the scientific/evidence-based justification for 'doing' PCH.

The economic justification

Globally, governments are actively exploring a range of methods to ensure that diminishing financial resources are employed to maximum effect. Until very recently, politicians and policymakers defined cost-effectiveness and service efficiency in terms of cost-reduction or, at the very least, cost containment. The last decade or so, however, has seen a partial conceptual shift towards

notions of *value* deriving from the pursuit of 'best practice' [62,63]. It would be premature to expect healthcare policymakers and clinical service managers to move away from the demand-led, supply-driven basis of current healthcare provision, given political objectives and the immediate service imperatives arising from the chronic illness epidemic. Nevertheless, we predict that a move away from a focus on volume and profitability of services provision, towards a preferential emphasis on superior patient outcomes, will soon become the dominant formula. A shift of services currently provided in the acute sector, to a provision within patients' own homes, will be one feature of the change we anticipate [64], an innovation that enhances patient autonomy, dignity and sheer convenience at the same time as reducing costs. In this context, PCH directly represents an operational tool through which to progress beneficial change, thus exemplifying its economic viability in parallel with an early stabilisation and subsequent reduction of healthcare costs [65-70].

It is in this context that we return to the challenge posed by the economic impact of the long term, chronic co- and multi-morbid, socially complex illnesses. The World Health Organisation warns that these conditions have the potential to bankrupt health services worldwide, making their financial implications as serious as their clinical consequences [43-48]. We know from the scientific/evidence-based justification considered above that PCH approaches to care have the ability to mediate significant changes in patient behaviour and in the nature of service use. The characteristics of these changes is such as to suggest a considerable - and highly positive - economic impact. Indeed, if the core principle of a value-based pursuit of cost-effectiveness is achieving the best clinical outcomes at the lowest financial cost, then the PCH model of care, which has the very real potential to contain healthcare costs, if not actually reduce them significantly, thus warrants immediate economic investigation. All new studies of the benefits of the PCH approach should therefore incorporate formal economic indices aimed at quantifying changes in resource utilization. The preliminary outcomes from such studies, pending larger scale economic investigations, will be vital in creating the political will necessary to fund the transformation of services in alignment with the PCH approach. Without such political will and the funding associated with it, person-centered innovations in clinical services are likely to remain small scale in extent and essentially local, providing only isolated examples of good practice which may or may not be utilized for the benefit of patients and health systems elsewhere.

How?

The question of 'How?' is quintessentially methodological in nature and, unsurprisingly, multifactorial. How does one justify 'doing' PCH? How are the limited number of individual tools for PCH currently being used? How are attitudinal and resource constraints impacting on the use of PCH tools? How can one refine these individual tools and piece them together into a coherent model of care to enable

a more comprehensive PCH assessment, response and follow-up? How do we identify the barriers to PCH implementation and how do we overcome such barriers? How do we allocate tasks to the multiple stakeholders necessary to drive PCH forward and coordinate them into a coherent team? Such questions are central to the introduction into practice of any innovation. For sure, the guiding principle when asking ‘How?’ is that change management of the type required for PCH needs a realistic, not utopian, vision when considering what can actually be achieved. Such an appreciation is vital within the current context of financially distressed healthcare systems, where staff morale, motivation and enthusiasm to fall behind and support new initiatives, is less than what might be considered optimal.

Yet despite the stressors inherent within modern health systems, there is increasing evidence of a significant commitment to PCH. Searches of electronic databases, using, for example, the term ‘person-centered’, show a near exponential rise in the use of the term over the last decade and in a variety of different contexts. Governments and commissioners of services routinely now employ the term ‘person-centered’ in their policy documents and public pronouncements, as do health and social care professionals, health service managers, policymakers, patient advocacy organisations, academics and the pharmaceutical and healthcare technology industries. Moreover, the terminology of person-centered healthcare, considered more broadly, is increasingly employed within mainstream medical and health sciences literature, so that it has now become possible to observe words and terms such as ‘accompaniment’, ‘empathy’, ‘patient activation’ and ‘shared decision-making’ appearing alongside terms such as ‘effect size’, ‘number needed to treat’, ‘relative risk ratio’ and ‘meta-analysis’. Such developments are of considerable significance [71].

Despite encouraging developments of this type, an ethical commitment to the principles of PCH is unlikely to go far without the availability of the necessary guidance and tools to enable operational implementation. At the current time, efforts to increase the person-centeredness of clinical services rarely extend beyond the administration of patient satisfaction questionnaires, the employment of patient-reported outcome measures and the use of option grids/decision aids as part of shared clinical decision-making. The use of these individual tools is far from consistent and routine, typically varying as a function of the characteristics of the clinical institution and the personal professional interests of individual clinicians. While efforts to employ any one of the individual PCH techniques we detail above is laudable, there is an urgent need to utilize or develop *de novo* a range of additional tools with which to elicit the patient’s narratives, values and preferences, means to understand their psychological, emotional, existential and cultural needs, methods to assess their relational and social functioning and methods to explore and respond to patients’ overall goals and life plans. Clinicians are eminently practical people and, if they are to practise in accordance with PCH principles in order to enable a more comprehensive assessment, response and follow-up of patients, then they need to be provided with

appropriate guidance in order to assist them. The question may be posed, then: “What guidance is currently available to assist clinicians and health systems to become more person-centered in their approaches - at the level of ‘hands on’ professional practice and in terms of service reconfiguration and delivery?”

PCH practice needs PCH guidance

Of the vast number of clinical practice guidelines produced over recent decades to assist clinicians in the management of disease, the greatest number focus on single diagnosis presentations, clinical states uncomplicated by the presence of multiple co-morbidities. The mono-disease focus of these guidelines renders them of highly limited use in the management of complex illness states such as the long term, co- and multimorbid, socially complex chronic illnesses, so that the effective clinician has, at the present time, to exercise skill and judgement and to act wisely, in identifying the precise needs of individual patients of this type. As a consequence, it is perhaps unsurprising that management is frequently suboptimal and outcomes often poor. Recognising the same, governments have sought to address, belatedly, the absence of clear guidance and to take action accordingly.

The NICE Guidance

The publication of recent documents urging clinicians to consider more closely the needs of chronically ill patients are better than no such documents at all, but their defining characteristic is their considerable generality. The recent guidance published by the UK National Institute for Clinical and Healthcare Excellence (NICE) in September 2016 is illustrative. Entitled ‘Multimorbidity: Clinical Assessment and Management’ [72], Guideline NG56 makes a series of suggestions on what patient care and clinical service organisation for multimorbidity should look like. The guidance emphasises the need to develop individualised care plans as integral components of treatment strategies and some key principles of PCH, including knowing the patient as an individual, the importance of understanding patients’ goals, values and priorities and the value of shared decision-making, are set out.

For sure, the decision to write NG56 recognises the scale of the chronic illness problem and the need to improve existing services. However, the guideline is heavy on general principles and exhortation, but light in terms of actionable methodology. No suggestions are given, for example, on how clinicians and service managers can particularise the general guidance to given clinical states and the broad recommendations advanced by NG56 do not come with practical methods and service audit indices attached. Indeed, the ability of clinicians and service managers to make changes to their ways of working in accordance with the guidance offered by NG56 is entirely assumed, so the relative absence of the necessary skills to do so and a deficit in the associated educational needs, as well as other key barriers to change, are essentially

unaddressed. How, then, can the care of the chronically ill be taken forward in such circumstances?

Particularising general principles to the management of specific clinical conditions

In order to address the question that we have posed, we respond with ‘particularization’. The NICE guidance, as we have seen, provides only general indications, basing its recommendations on *some* key components of a person-centered approach, while omitting or remaining unaware of the many others [72]. But, if PCH is not comprehensive, it is nothing. Indeed, partial approaches to PCH are, by definition, inadequate for a technique which is holistic by its nature. If, then, a partial approach is all that can reasonably be achieved at a particular juncture, for whatever reason, then it must surely be seen as essentially preliminary in initiative, functioning temporarily in advance of more complete strategies for comprehensive assessment, response and follow-up. Given the generality of the NICE guidance it is necessary, therefore, to take as many if not *all* of the multiple components of the PCH approach, not simply a few prominent examples, and to directly particularise them to the management of specific clinical conditions. The ESPCH, since its inception, has recognised the need to adopt such an approach and, for this reason, as part of its 10-year Strategic Plan (2014 - 2023), has commenced work on developing the associated methodologies.

(1) Mapping deficiencies and deficits, highlighting excellence, closing the gaps

Working in direct collaborative partnership with major clinical societies, advocacy bodies and patient charities across the globe, the Society will, for given principal clinical conditions, undertake an initial mapping exercise, designed to identify the common deficiencies, gaps and frank deficits in the person-centered care of the given condition (remaining fully mindful of co- and multimorbid complexities), in parallel identifying examples of good practice and clear excellence. This process will be achieved through an *International Conference* bringing together key leaders in the field drawn from the multiple stakeholders in any authentic PCH approach - clinicians, health service managers, patients and patient advocacy organisations, family and professional carers, social care professionals, faith-based workers, politicians and policymakers and the pharmaceutical and healthcare technology Industry as a whole. The presentations at the *International Conference* will be published formally as special sections/supplements within the *European Journal for Person Centered Healthcare*, the official journal of the Society, ensuring worldwide availability of the discourse.

(2) ESPCH Clinical and Service Guidance Development Groups (CSGDGs)

Following the *International Conference* and in assimilation of its voices and advice, the Society will constitute a *ESPCH Clinical and Service Guidance Development*

Group (CSGDG), under a dynamic chairmanship drawn from the field, with the specific aim of steering the development of clear and particularised guidance for an enhanced person-centered care of the given condition. When drafted, and following external consultations and accompanying revisions, the Guidance will be published by the ESPCH as an Official Document in both electronic and hard copy versions, representing a trusted and independent resource to assist clinicians and service managers in increasing the person-centeredness of services for the given condition. If, for example, the guidance focusses on the person-centered care of multiple sclerosis, then the document will be published as ‘European Society for Person Centered Healthcare – Clinical and Service Guidance - Multiple Sclerosis – 2017’, routinely referred to as ESPCH - CSG - MS - 2017. For a project devoted to breast cancer, the guidance would, in additional example, be published as ‘European Society for Person Centered Healthcare - Clinical and Service Guidance - Breast Cancer - 2017’, routinely referred to as ESPCH - CSG - BC - 2017. And so on, with reference to the wide range of other long term, co- and multimorbid, socially complex illnesses which the Society is currently preparing to study.

(3) Upskilling clinicians and service managers/users in the ESPCH Guidance - ESPCH Masterclasses

Following the publication of the ESPCH guidance documents, the Society will organise multiple *Masterclasses*, to be held in strategically key countries, in order to upskill clinicians and service managers/users in the implementation and operational use of the Guidance. The two-day masterclasses are essentially intensive training sessions limited to 20 attendees per masterclass and will be delivered by a core teaching faculty of distinguished clinicians and other stakeholders in the PCH approach, chaired by a respected opinion leader from the host country. Having attended a masterclass, upskilled colleagues will be able to return to their respective home institutions and environments as mentors, teachers and leaders, thus able to inspire, teach and lead their colleagues, students and others - intra-institutionally and also locally and regionally. The ESPCH envisages each of the principal conditions-specific projects to be updated on an annual basis and so, over a short period of time, the Society intends that many hundreds of clinicians and other stakeholders will be equipped with the necessary skills to increase the person-centeredness of care. In a very real sense, these colleagues will become the ‘trailblazers’ for a newer, more sophisticated approach to the service of the sick, that elevates legally competent practice to an altogether higher order of skill. When good practice has been propagated in this way, measurable changes in service quality will begin to emerge.

(4) Auditing progress against ESPCH Guidance and documenting its outcomes

The ESPCH envisages that clinicians and service managers/users will wish to audit their performance against the specific recommendations of the ESPCH

Guidance and, for this reason, each ESPCH Guidance Document will include, at its conclusion, an Audit Proforma with the explicit intention of encouraging users to audit their performance against self and institutionally agreed standards in order to quantify the degree of success in implementing PCH-type approaches. Moreover, the Society believes it necessary that in addition to the use of such process measures, suitable research, varying in scale according to local constraints, will aim to quantitatively measure and qualitatively describe the improvements in clinical outcomes that are likely to result from the implementation of the Guidance. Such data, when, analysed and collated across organisations, are essential in developing the empirical justification for a continued and more widescale implementation of the PCH approach.

Conclusion

The clinical professions, when consulted, continue to subscribe to the ultimate goal of healthcare: to attend to the sick with all of the resources, intellectual and practical, that are available. Yet a continuing depersonalization, increasing super-specialisation and progressive siloization, together with a disconnection between health and social care systems, demonstrates a clear mismatch between what clinicians and health systems claim to believe and how they operate in the context of everyday practice. It is no surprise, then, that in these circumstances patients complain that they are treated not as persons, but rather 'dealt with', 'processed' even, as subjects, objects or complex biological machines. For sure, it is difficult to argue against the contention that a medicine that is rich in technical skill, yet poor in humanity, is far less than first rate. Such a medicine needs significant overhaul, if not substantial change, in order to step up to the challenge of chronic illness management in a manner that it has by no means yet demonstrated itself able to do.

Given the accumulating empirical research base, which increasingly demonstrates the ability of PCH approaches to generate a wide range of superior clinical outcomes above those possible through 'care as usual', and at potentially contained or lowered costs, PCH can no longer plausibly be understood as an option, but rather as an integral clinical competency that sits alongside a purely technical expertise and in functional integration with it. To treat patients as persons is, for the reasons we have discussed, not an unachievable ideal or the latest 'fad' or 'fashion' in healthcare, but rather an imperative that should in due course come to be established as a mandatory competency on which revalidation processes by professional regulators can be based in significant part and directly alongside assessments of technical clinical skills. Moreover, it is the Society's view that commissioning authorities should decline to continue purchasing a lower denominator 'care as usual', in favour of a higher numerator 'person-centered' delivery. In this, both regulators and commissioners will surely be supported by patients, who have called time on 'medicine as usual', requiring, even

demanding, not a 'medicine of the disease', but a 'medicine of the whole person'.

The growing calls for PCH are changing the nature of modern healthcare and a seismic shift from physician-centric medicine to person-centered healthcare is currently taking place within international health systems. As part of this shift, PCH is moving from strength to strength, being increasingly understood as a powerful means of addressing the greatest challenge which confronts healthcare systems today - the long term, chronic co- and multimorbid, socially complex illnesses. There is a need to move towards the operationalisation of PCH in order to reap its benefits and it is precisely this process in which the ESPCH has become engaged as part of its 10 Year Strategic Plan (2014 - 2023). The Society is confident that its systematic and cohesive approach to facilitating progress in the person-centred care of specific clinical conditions will, unlike the haphazard and undetailed initiatives undertaken elsewhere to date, achieve changes of clinical merit and operational sustainability, moving rhetoric to methods, through implementation to outcomes.

Conflicts of Interest

We declare no conflicts of interest

Note to Readers

The ESPCH welcomes enquiries into its work and suggestions for collaboration. In addition to the major programme of work on the long term co- and multimorbid socially complex illnesses discussed above, the Society is currently engaged in establishing a university-based *International Centre for Person-Centered Healthcare Policy, Practice, Teaching and Research* and also a *Master's Degree on Person Centered Healthcare* with Diploma and Certificate options (with face-to-face taught and also distance learning options).

Forthcoming publications of the Society include a major *Lexicon and Dictionary of Terms for Person Centered Healthcare* and a Three Volume Textbook on *Person Centered Healthcare - Essentials of Theory and Essentials in Practice* which will constitute the most seminal text yet to be published in the field.

Colleagues interested in joining the ESPCH at any of its varying membership levels, or in donating to or sponsoring its ongoing work, are invited to contact Professor Andrew Miles at: andrew.miles@pchealthcare.org.uk

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