Formative Care: Rethinking the medicine of frailty.

Abstract

The care and support of the increasing ill, frail and dependent population, is poorly served by orthodox health and social care. Policy initiatives such as the integration of the funding of health and care services, admission avoidance schemes and improved end of life care are generally reactive to a service problem as opposed to patient need. What has been lacking generally has been an understanding of the dependent population and the potential for developing a positive proactive approach to wellbeing and life quality in lives reframed by frailty and dependency.

It is proposed that the term “Formative care”, would bring distinction from traditional health and care strategies of prevention, diagnosis, treatment, rehabilitation, palliative and end of life care.

The use of life trajectories of older people can help define the population of the frail for whom new formative approaches to health may be effective and in the absence of clear clinical markers that define the limits of traditional medical approaches, the watersheds of social transitions may provide a prompt for the institution of a formative approach to health and care.

Recognising the health and care space for a formative approach to health and care may facilitate a coherent approach to the development of understanding, policy and practise and will necessitate new research to inform best practise.

Keywords: frailty*, well-being, life quality, life trajectories, care homes, clinical purpose, integration, treatment strategy,*

Introduction

Modern Medicine generally can be described in terms of prevention, diagnosis and the evidenced treatment of acute and long term conditions. Additionally and particularly for older people needs assessment, rehabilitation and good end of life care are well established. These clinical domains are broadly mirrored in social care where prevention, personalisation, enablement, empowerment and risk management are commonly cited.

The early days of Geriatric Medicine highlighted the importance of assessment, treatment and rehabilitation for reducing dependence on care (1) as has the improvement of living conditions and general support (2). Collectively, these have successfully limited avoidable dependency. However, ageing populations feature a growing number of older dependent people who are increasingly unresponsive to traditional treatment(s) but for whom dying and death is not imminently anticipated. This emerging population of the frail old is increasingly becoming recognised (3) as is the complexity of managing multiple morbidities (4). However, there is little

coherence to the purpose of medicine for this population in spite of frequent public, professional and political concerns with common themes of dignity and needs, quality of life and affordability(5).

The continued use of the denominator of age without qualification by clinical and socio-economic circumstances creates uncertainty for policy makers, should they plan for a healthy ageing population, a dependent one or a mix and if so what proportion? Persisting difficulties in achieving a sustainable funding solution for long term care may be in part rooted in mixed demographic/epidemiological messages and uncertainties of what is required now and in the future for an increasingly aged society.

Life trajectories to death and medical responses

It is widely recognised that multiple morbidities increasingly complicate health and the specialist treatment of multiple diseases in specialist silos is increasingly questioned (4). The analysis by Lynn and Anderson (6) of the trajectories of a large group of US Medicare (an older population) beneficiaries tracked towards their death provides a compelling classification of the clinical pathway to death of an ageing population. Four broad categories were identified,

- 20 per cent of deaths followed an illness such as cancer that is characterised by a clear clinical transition from living with to dying from a condition that has an unrelenting progression. In the UK this group will be recognised as having benefited from the development and increasing availability of palliative and hospice care.
- 20 per cent of deaths were related to progressive long-term conditions complicated by acute exacerbations during which an increasing likelihood of death is recognised, for example Chronic Obstructive Pulmonary Disease. People in this category are likely to be in programmes of chronic disease management where the limits of treatment and likelihood of dying and its nature are understood by specialists, primary care and crucially by patients and their families, enabling their care and support needs to be informed by this condition.
- 20 per cent of deaths were classified as “sudden”, for example a fatal myocardial infarction or an accident. For this group preventative medicine and continued developments in safety may yield further reductions.
- The largest group of 40% were poignantly described as dying after a period of “progressive dwindling”. This group are typified by people with conditions such as Alzheimer’s disease and other degenerative conditions that are individually or collectively progressively disabling. It is this population that forms the greatest collective demand of health and care support over long periods and the population that is the prime concern of this paper.

<u>The growing importance of progressive frailty</u>

As progress continues to be made in the treatment of diseases that have previously dominated mortality in later life the importance of conditions individually and

collectively that lead to dependence and frailty will grow both proportionally and absolutely.

For life trajectories such as cancer or chronic progressive conditions clinical watersheds are often identified for example, the disease progression that triggers a clear change in the rationale and expectations of treatment and care exemplified by cancer that becomes unresponsive to treatment creating a “watershed” to palliative care and end of life care. The clarity of this “watershed” approach has transformed care at the end of life in Cancer but it has been extended, somewhat uncritically, to the progressively frail. Very frail patients may have a life expectancy of several years and are certainly not “actively” dying.

Traditional health, care and frailty

Evidence based medicine is generally based on “intention to treat” trials where outcome benefits are sufficient to justify the risks of treatment and costs. Evidence for sustained treatment of conditions over long periods often into great age often rest on an extrapolation of evidence which may be tenuous in advanced frailty often complicated by co-morbidities. Furthermore, the responsiveness of many diseases to treatment often diminishes with disease progression and proven benefits may increasingly become blurred or outweighed by adverse effects. The unacceptability of excluding older people from research is becoming increasingly recognised (7).

Often discharge notes from hospital of frail patients, particularly when transferred to care homes infer that, “nothing more can/could or should be done”, yet patients typically will be on an extensive list of treatments and subject to varying degrees of planning for the end of life. This is a bleak and confusing approach and the uncertainty it creates may contribute both to the application of care pathways for end of life care when the diagnosis of dying is uncertain (8) and the right to determine death debate. The majority of these frail patients are entering an emerging “medical space” where the medical purpose needs both clarification and communication. The expression “enabling the best possible life quality and experience in the context of a life reframed by frailty” captures the essence of what many practitioners intuitively think and often practise. Calling this a “Formative” approach to medical care may help distinguish it from palliative and end of life care and the more established diagnosis and treatment of modern medicine.

Social watersheds and formative medical care

Progressive frailty seldom exhibits a clear clinical watershed although one may be identified in retrospect. However, progressive frailty is often accompanied by social watersheds of which admission to a care home for long-term care is perhaps the most readily identifiable. Care Home admission usually follows assessment(s) that centre on eligibility and the seeking of opportunities through treatment and rehabilitation to avert admission rather than the on-going health care. An individual

with dementia may require the sanctuary and support of a care home for an average length of stay of some 20 months. Whilst the importance of good end of life care is acknowledged, active dying will only occupy a small percentage of that stay, so for the greater part of residence a clinical approach that seeks to optimise quality of life seems obvious but poorly stated. If Care Home admission were to be established as a an initial trigger for the “Formative” approach increasing knowledge could develop understanding of when a transition to a formative approach may be appropriate more widely in the community.

The following case vignettes illustrate a “Formative” approach to medical care following admission to a care home,

- The person with dementia has been treated with sedation in the community to enable family carers to cope with disordered sleep pattern. A combination of carer exhaustion and disease progression in spite of maximal support necessitates care home admission. Sedation is withdrawn and whilst sleep patterns remain considerably disturbed the twenty four hour care can accommodate this and the person’s behavioural pattern improves such that day trips with family become possible. The individual remains dependent on care but their life quality becomes much improved.
  Note: 75% of prescriptions for antipsychotic medication of care home residents are initiated prior to admission to the care home (Personal communication Pharmacy Plus December 2011)

- The person with increasingly poor mobility related to long standing Parkinsonism whose treatment has been escalated in an attempt to maintain mobility sufficient for family to support at home develops a treatment related psychosis and is admitted to a care home. With 24 hour access to 2 carer enabled transfers treatment is reduced, whilst physically dependent lucidity is regained to enable meaningful socialisation. Note: overall 5% of care home residents are diagnosed with Parkinsonism (9)

- The malnourished person with advancing frailty, mild confusion and repeated falls is admitted on long term treatment with beta blockers for hypertension and Statins for cardiac risk and dietary supplements. The patient exhibits postural hypotension and so the beta blockers are discontinued as are the Statins and supplemental feeds. Meal times are supervised and the patient gains weight and strength to the extent that after several months they are discharged home lucid and independent with no on-going support. It is unclear whether the improvement of mental state has been due to improved cerebral perfusion or a beta blocker related pseudo-dementia.

The clinical interventions described are distinct active interventional approaches that are not easily classifiable in common approaches to medical practise, though experienced Geriatricians and General Practitioners will recognise them. They all illustrate an active approach that seeks the “best deal” for the patient in the context of their circumstances and are about optimising well-being and whilst evidence of

inappropriate prescribing is recorded (10) guidance on positive drug withdrawal is lacking (11). The altered nature of therapeutics in frailty is starting to be recognised as a dark corner of medicine with calls for trials to clarify the effective and ineffective use of medicines in older people (12). There is evidence to support systematic discontinuation of medication in older people who present for geriatric assessment within the community (13) but such work needs to be undertaken on a larger scale before robust guidance can be constructed.

Making formative care evidence based

Developing a practice of Formative care for the frail will require systematic programmes of research into the withdrawal of treatment and the benefits of various interventions, to develop guidelines. Such trials are unlikely to be funded by Pharmaceutical companies but as electronic records of prescribing and care become more accessible and both the relative ease of access to care home residents many traditional difficulties may be overcome. Furthermore, new treatments targeting conditions such as established and advanced Alzheimer's data from assessments could, at scale, provide not only disease registries but a means to investigate new interventions against a contemporary database.

This approach focuses initially on care home residents it is important to recognise that in the UK the number of care home beds exceed all NHS beds by more than three times and that some 80% of the adult social care budget is currently committed to the funding of care home places care homes. Whilst prevention, re-ablement together with good palliative and end of life care remain crucial an evidenced "Formative" approach proposed will reduce futile and expensive medical treatments as well as promote well being and maintain outcomes as proactive managed care approach has already been proven to deliver (16). Substantial savings will accrue from the reduction of ineffective prescribed drugs. With over 400000 residents in care homes presently prescribed an average of 7 items potential savings of £100 million annually to the drug bill and considerable reductions in acute hospitalisations as a result of iatrogenic disease projected.

Conclusion

The lack of systematic approach to the health and care of the frail is a contemporary demonstration of the inverse care law (17). The use of a social watershed as a trigger for a developed "Formative" approach the medical care of people resident in a care home promises a rare combination of improved patient well being, a positive new medical purpose.

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