

# Formative Care: defining the purpose and clinical practice of care for the frail

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## Introduction

The emerging population of older people with chronic, progressive degenerative diseases pose the greatest challenge to the sustainability of health and care systems but services are not well developed for their needs<sup>1,2</sup> and robust metrics of experience lacking. 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, palliative and 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 phase of Geriatric Medicine highlighted the importance of Comprehensive Geriatric Assessment, treatment and rehabilitation in reducing care needs<sup>3</sup> and the improvement of living conditions and general support.<sup>4</sup> Collectively, these have successfully limited avoidable dependency. In recent years, development has focused on improving end of life care. 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 dependent population is increasingly recognized<sup>5</sup> as is the complexity of managing multiple morbidities.<sup>6</sup> 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, quality of life and affordability.<sup>7,8</sup> The continued major failures of care<sup>9</sup> and inadequate clarity over life status<sup>10</sup> or monitoring measures to assess experience<sup>11</sup> all point to a need for new thinking in this ‘clinical space’.

## Life trajectories to death and clinical responses

Lynn and Adamson<sup>12</sup> analysed the life trajectories to death of a large group of US Medicare beneficiaries (an older population) describing four broad trajectories of dying in an ageing population that provide a useful insight to the understanding of the characteristics of older people and the services they need.

- 20% of deaths followed illnesses such as cancer characterised by a clear clinical transition from treatable to unrelenting progression. This group will be recognised as having benefited from the development and increasing availability of palliative and hospice end of life care.
- 20% 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. Patients in this group were likely to be in programmes of chronic disease management where the limits of treatment and likelihood of dying are understood by specialists, providers and crucially by informed patients and their families, enabling planned care and support.
- 20% of deaths were classified as ‘sudden’, for example a fatal myocardial infarction or an accident. Preventative healthcare and improved safety may further reduce this group.
- The largest group of 40% were poignantly described as dying after a period of ‘progressive dwindling’. Typically, these are 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 focus of this paper.

## The rising importance of progressive dwindling

As progress continues to be made in the treatment of diseases that have previously dominated mortality, the importance of conditions individually and collectively that lead to frailty and dependence will grow both proportionally and absolutely.

Clinical treatment of frail dependent patients lacks an underpinning evidence base. Evidence-based medicine is generally based on 'intention to treat' trials where continued treatment of conditions over long periods often rests on an extrapolation of evidence which may be tenuous in later life complicated by co-morbidities and frailty, and the responsiveness of many diseases to treatment often diminishes with disease progression and benefits blurred or outweighed by adverse effects. Discharge notes from hospital of patients, particularly when transferred to care homes infer that, 'nothing more can/could or should be done', yet typically they will be accompanied by an extensive list of active treatments and subject to varying degrees of planning for the end of life whilst lacking systematic guidance or advice on how clinically well-being and experience may be optimised or maintained. The uncertainty of the clinical space between modern medicine and end of life care has been a factor in the discrediting of the Liverpool Care Pathway,<sup>10</sup> a factor in the 'right to die' debate. Frail, dependent patients and their families need clarification of their health status, expectations and the purpose of clinical care.

We propose the purpose be expressed as 'Enabling the best possible life quality and experience in the context of a life reframed by frailty and dependency'. We acknowledge this captures the essence of what many practitioners intuitively think and practise but think naming this 'Formative Care' may help distinguish it from modern medicine and end of life care and promote common understanding.

## Social watersheds and formative medical care

The insidious development of dependence is often accompanied by social 'watersheds' of which admission to a care home for long-term care is perhaps the clearest. Care home admission usually follows assessment(s) that centre on eligibility and the seeking of opportunities to avert admission through interventions rather than specifying ongoing healthcare. An individual with dementia may require the sanctuary and support of a care home for 20 months, active dying will only occupy a small percentage of that stay. For the greater part of that time, Formative Care may seem obvious yet it is presently

poorly stated. Admission to a care home for long-term care could provide a trigger for Formative Care and this common purpose aligns practitioner individuals and their families and friends and build confidence through reducing uncertainty. The following case vignettes illustrate clinical Formative Care approaches following admission to a care home,

- An individual with dementia sedated in the community to enable family carers to cope with a disordered sleep pattern. A combination of carer exhaustion and disease progression in spite of maximal support leads to care home admission. Sedation is withdrawn and whilst sleep patterns remain considerably disturbed, the available 24-h care can cope and as behaviour improves day trips with family become possible. The individual remains dependent on care but their quality of life is much improved. Note: 75% of prescriptions for antipsychotic medication of care home residents are initiated prior to admission to the care home.<sup>13</sup>
- The person with increasingly poor mobility related to Parkinsonism whose treatment has been escalated to maintain mobility sufficient for family to support at home develops a treatment related psychosis and is admitted to a care home. Sedation is withdrawn and whilst the individual's sleep pattern remains disturbed the presence of 24 hour care can manage and overtime behaviour and daytime awareness improves such that day trips with family are possible. Note: overall 5% of care home residents are diagnosed with Parkinsonism.<sup>14</sup>
- 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 ongoing support. It is unclear whether the improvement of mental state has been due to improved cerebral perfusion or a beta blocker related pseudo-dementia. Note: whilst unclear whether an individual or collective medication related problem, pseudo-dementia has been reported with B blockade, Statins are recognised as causing muscle pain and weakness and hypotensive treatment can be withdrawn with no recurrence of hypertension in some patients.

The clinical interventions described are distinct active interventional approaches that are not easily

classifiable in present medical practice, though experienced Geriatricians and General Practitioners will recognise them. They illustrate a quest for the ‘best deal’ for the patient in the context of their circumstances and are about optimising well-being. These cases have a clinical profile of ‘progressive dwindling’ and illustrate the social watershed of care home admission to institute a distinct and positive clinical intervention.

Inappropriate prescribing is well recognised<sup>15</sup> but evidence-based guidance on positive drug withdrawal is lacking.<sup>16</sup> 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.<sup>17</sup> There is some evidence to support systematic discontinuation of medication in older people who present for geriatric assessment within the community,<sup>18</sup> but more research is needed before robust guidance can be constructed.

## Developing Formative Care

Little is known about the nature of current practice and decision making in frailty. Developing a systematic approach to Formative Care will require programmes of research into various interventions, to develop clinical guidelines.

Care homes offer a good resource for research. In the UK, the number of care home beds exceeds all NHS beds by more than three times. Developing Formative Care should reduce futile and expensive treatments and admissions as well as promote well-being and positive outcomes. Experiences from proactive approaches to care home resident medical care do support this.<sup>19</sup>

## Conclusion

The growing population of dependent ‘dwindling’ older people are not well served by the existing medical approaches. ‘Social watersheds’ may provide triggers for the institution of Formative Care wherein the optimising of quality of life and experience becomes a prime purpose for health and care.

Identifying the target population for Formative Care through the synthesis of diagnostic groups, likely trajectory and social transitions, starts to open the possibility of systematic approaches for positive clinical interventions. It is recognised that there is little evidence at present, but the opportunity of developing this through research would be greatly enhanced by the population being readily identified and makes a strong case for supporting the implementation of electronic care records and standardised assessment processes.<sup>20</sup>

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