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THE MORE THEY NEED CARE, THE MORE THEY STRUGGLE TO RECEIVE IT. OLDER PATIENTS AND THE INVERSE CARE LAW

abstract

Universal health coverage (UHC) is the condition in which every member of a certain community have access to essential, effective care without financial hardship.

Increasing older adults suffering from chronic morbidities and/or social isolation struggle to receive the care they need precisely when they need it most. These patients need care personalization, multidisciplinary integration and professional cooperation more than high-tech biomedical treatment, as plenty of social determinants frequently hamper the effectiveness of each single treatment received. If the health inequalities resulting from suboptimal organization of care can be reduced, taking action becomes a question of social justice.

This paper aims to 1) describe some relevant determinants of health that prevent many older adults from receiving the care they need, 2) outline some policies to avoid ageism and minimize rationing.

keywords

ageing, health care rationing, health inequalities, social determinants of health, social prescribing

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1. Introduction

According to the World Health Organization, Universal Health Coverage (UHC) is the condition in which every member of a certain community have access to essential care of quality enough to be considered effective, without financial hardship (World Health Organization, 2023). Good health is key to seize opportunities and perform tasks relevant to the individuals concerned, and each solidaristic healthcare systems is based on the right to receive (at least) essential healthcare, whether this is guaranteed by social insurance or by National Health Service (NHS) (Pennestrì, 2023). The first NHS in history, for instance, was adopted by the United Kingdom (UK) to face the five giants of “want, ignorance, squalor, idleness and disease” (Beveridge, 1942). In Italy, health care is a social right supported by the Constitutional principles of solidarity (art. 2), equity (art. 3) and safety (art. 32), which the Italian NHS is expected to cover since 1978 (L. 833/1978).

In 1971 Julian Tudor-Hart, Welsh physician, health policy researcher and activist, formulated the inverse care law, according to which “the availability of good medical care tends to vary inversely with the need for it in the population served”, as a consequence of market influence, waiting lists, professional shortage, facility location and quality of care (Tudor Hart, 1971). The key role of social determinants of health - place of birth, income, education, family composition - on disease onset, access to care and preventable mortality had indeed been demonstrated by impressive epidemiology, public health and distributive justice literature, including John Chadwick, Michael Marmot, Amartya Sen, Norman Daniels, Barbara Starfield, Greg Bognar and Iwao Hirose (Bognar & Hirose, 2014; Daniels, 2008; Marmot *et al.*, 1978; 1991; Porter, 1996; Sen, 1993; Starfield, 2011).

Today, older adults affected by chronic disease(s) and/or social isolation are the individuals who struggle most to receive the care they need, international literature and policy reports demonstrate (Pennestrì, 2021; Lawless *et al.*, 2020; Consorzio Nazionale delle Associazioni dei Malati Cronici & CittadinanzAttiva, 2015; Fosti & Notarnicola, 2014; Starfield, 2011). These patients usually suffer from multiple chronic diseases, need consultations from different healthcare professionals, face continuous outpatient visits, undergo more or less appropriate diagnostic examinations, need multiple drug prescriptions and frequent General Practitioner (GP) surgeries; they also need someone who help them move from facility to facility, provide social support and help perform the activities of day living (ADLs), either direct (i.e., eating, washing, cleaning) or indirect (i.e., doing the shopping, paying the bills, buying the drugs).

Missing one step of the so-called “healthcare journey” can cause preventable hospital admissions, inappropriate emergency department (ED) visits, unexpected complications and premature death. Therefore, implicit rationing mechanisms (e.g., service fragmentation, underfunding, doctor-patient miscommunication and waiting lists) put these patients in a position to rely on their own financial, societal, educational and family resources, like purchasing private care to reduce waiting time, consulting a professional they personally know for advice, having a sure point person in case of emergency. Care givers, in turn, suffer from anxiety, work-assistance incompatibility, overwhelming pressure and double care giving.

The impact of ageing and chronic disease on society is so serious as to threaten the sustainability of solidarity systems, called to meet the growing healthcare demand using limited resources. This is why explicit rationing strategies based on the maximization of life expectancy and quality gain importance (Harris, 1987), along with the arguments of fair innings (Bognar, 2015; Davies, 2016) and lifestyle responsibility (Pillutla *et al.*, 2018). If we adopted a utilitarian approach to the allocation of limited healthcare resources, older adults will be subject to both age (ageism) and disability (disablism) discriminations (Tsuchiya, 2000; Singer et al., 1995), as they have reduced life expectancy often characterized by poor autonomy and chronic disease (Bognar & Hirose, 2014; Organization for Economic Cooperation and Development, 2015). The fair innings argument, in turn, holds that older adults receive less priority treatment than younger patients (Bognar, 2015).

Before giving older individuals lower priority of care it is possible to focus on implicit rationing mechanisms and try to minimize them. Health inequalities resulting from improvable care organization are considered inequities whose reduction is a question of social justice (Daniels, 2008; Braveman & Gruskin, 2003; Angeli *et al.*, 2021).

Understanding the specific vulnerability of older adults, taking care of them and adopting dedicated policy measures are the actions recommended by a systematic review on vulnerability in aged care (Sanchini *et al.*, 2022). This paper aims to describe some relevant determinants of health that prevent many older individuals from receiving the care they need (both in terms of disease onset, paragraph two, and access to care, paragraph three), and outline some policies (paragraph four) to prevent or minimize ageism and explicit healthcare rationing.

2. Living more, living worse: social determinants of health in the onset of disease

Seventy years of astonishing biomedical progress saved millions lives either by defeating common deadly infections through antibiotics, serotherapy and vaccines, either by taking advantage of DNA science and technology. Previously fatal acute diseases became chronic medical conditions (i.e., diabetes and kidney failure) and previously chronic, degenerative rare diseases became a common side-effect of extended life expectancy itself (i.e., neurological disorders, musculoskeletal disorders and cancer).

Beyond a certain age, more life expectancy hardly coincided with healthy life expectancy, however. The onset of multiple chronic morbidities (Starfield, 2011) expose older adults to sudden acute episodes and complications, causing psycho-physical dependency on care givers and worse health perception given the same disease (Istituto Nazionale di Statistica, 2017a). For instance, Italy is among the first European countries for life expectancy at birth, but remains below the average when considering functional limitation rates from age 65 years onwards (Organization for Economic Cooperation and Development, 2015). In some Regions like Lombardy, which makes up 1/6 of the Italian population, 1/3 inhabitants suffer from one chronic disease at least, 30% patients consume 70% of healthcare resources (approximately 19 billion € in 2019) and patients aged 70-74 are those who absorb the largest part of them (Pennestrì, 2017).

Education and financial resources also influence the onset of chronic disease. 53% of Italian chronic patients have a lower educational qualification (primary school or none) (Istituto Nazionale di Statistica, 2017b), 18.3% of patients affected by three or more diseases live in financial hardship (Ministry of Health, 2016) and 3 million patients gave up seeking treatment because healthcare pathways were too complex to follow or too expensive to afford, even when the largest share was covered by the NHS (Consorzio per la Ricerca Economica Applicata in Sanità, 2015). Hypertension, one of the most common chronic disorders, mainly affects elderly women and poorly educated, low-income individuals (Ministry of Health, 2016). Hip fractures are favored by age and age-specific psycho-physical fragility conditions such as osteoporosis, dementia, preventable falls and isolation, causing a 24-months mortality increase even after effective and timely surgery (Viganò *et al.*, 2023): patients discharged from hospital usually fear another traumatic fall and another hospitalization; therefore, they reduce basic physical activity and socialization, stay at home, sitting or bedridden, further weakening their bones, let aside depression, sense of uselessness and cognitive dysfunction, which often end up in another traumatic fall.

Chronic disease, weak mental health, isolation and poor financial resources feed each other. A systematic review on 70 international reports involving more than 309.000 people found that lack of strong relationships increased the risk of preventable death from all causes by 50%, an effect greater than obesity and roughly comparable to smoking up to 15 cigarettes a day (Holt-Lunstad *et al.*, 2015). In other words, the farther you live from your person point, the more likely you are to die prematurely, either because you are assisted too late, or out of the fear that this will happen (Pennestrì, 2021).

3. Long-term (winding) care: social determinants of health in the access and prosecution of care

Patients with multiple chronic diseases possibly aggravated by social isolation require multidisciplinary interventions and substantial integration between healthcare treatment and social support. Long-term care or social-health care have been defined as “all [the] activities aimed at satisfying, through integrated care pathways, the health needs of the person who jointly require health services and social protection actions capable of guaranteeing, even in the long-term, the continuity between treatment and rehabilitation actions” (Legislative Decree 299/1999, art. 3-septies).

Long-term care combines *socially-relevant health services* (remove or control pathological symptoms that impact quality of life) with *health-relevant social services* (remove or minimize the socio-economic barriers which hamper optimal treatment and rehabilitation outcomes). The effectiveness of long-term care largely depends on how each pathway is organized, financed and provided to patients, and comparative policy studies performed in France, Germany, Italy and UK show how large is the population who is underserved or served late (Fosti & Notarnicola, 2014). Fragmented care pathways can compromise UHC: on the one hand because care outcomes depend on the ability of patients to recompose the individual plan; on the other hand because of the inappropriate ED visits, prescriptions and diagnostic examinations which usually follow. An estimated 80% of the UK public expenditure comes from imaging and laboratory diagnostics (O’Sullivan *et al.*, 2018), among which up to 50% high-tech imaging tests resulted unnecessary, but triggered further treatments and diagnostic investigations equally unnecessary (Rao & Levin, 2012). The less appropriate medicalization, the less health for patients and the greater waste of resources which may benefit other patients; to put it in the words of the European Commission Expert Panel on Effective Ways of Investing in Health (EXPH), the more expenditure, the less personal, technical, allocative and societal value (EXPH, 2019).

Implicit rationing mechanisms harm older patients in need of long term care at different levels, a policy study reports (Fosti & Longo, 2013), most of which are reflected by older patients themselves (Lawless *et al.*, 2020):

- At the *personnel* level, the main problem is poor interprofessional coordination (e.g., between GP and specialist(s), between different specialists, between primary care and hospitals, between acute and intermediate care, between health and social care institutions). In this case, older adults need to recompose the healthcare pathway on their own, clinically relevant information may be lost from personal history and unnecessary or incompatible treatments (e.g., drugs) can be prescribed. Older adults dislike "to repeat (always) their story" (Freeman & Hughes, 2010).

- At the *tariff* level, the main problem is the patient's (or care giver's) inability to bear ongoing out-of-pocket expenditure, whether it is a low but continuous share of the overall public expenditure or whether it is the entire payment of private providers to fill the gaps of public service (i.e., access diagnostic examinations on time, social support across the transitions, home or residential care).
- At the *communication* level, the main problem are healthcare professionals and employees who do not explain key information on post-hospital discharge treatments and pathways as clearly and comprehensively as they should, compromising patient compliance, preventing vulnerable patients to raise questions and undermining the care giver's ability to help them at home. Healthcare institutions can also be responsible of ineffective communication strategies, e.g. when some services are available but neither patients, nor care givers are aware of it.
- At the *layout* level, the time and place where care is delivered is the main physical barrier. Healthcare facilities need above all to be clearly identifiable and user-friendly for patients with walking, continence, memory, sight disabilities, fatigue and different degrees of impairment (parking, building distribution, internal divisions, transitions from reception to medical surgeries). Moreover, older patients are often accompanied by partners with similar problems. Outpatient care schedules frequently overlap with the working hours of sons, daughters and informal care givers, who may opt for a part-time employment to help their parents, not to consider the time withdrawn from children they can have in turn. Formal care givers can be hired but they need out-of-pocket remuneration (tariff level) or efficient integration with social institutions when free (personnel and communication levels).

4. Reducing health inequalities through dedicated policies

The previous two sections should have clarified why effective individual treatments can be vanished by suboptimal organization of older patients' care.

Chronic care management programs can tackle implicit rationing at the personnel level. These programs share a) a clinical manager who evaluates the multidimensional needs of the patient, and plans a personalized care pathway accordingly; b) a case manager who helps the patient comply with the plan (reminding the patient of visits, periodical examinations and the renewal of prescriptions, for example) and works as a person point for common questions about symptoms and treatment; c) a care manager who provides the entire set of treatments prescribed by the clinical manager, e.g., supplying GP surgeries, basic diagnostic examinations, physical therapy, outpatient specialized care, social and psychological support at the same place (Pennestrì & Banfi, 2023; Pennestrì & Banfi, 2022). A comprehensive care budget can be introduced to take charge of all patient needs included in the personalized plan (drugs, outpatient visits, hospitalizations, social care). Remuneration can be tied to the achievement of pre-established care outcomes such as better clinical parameters, reduced hospitalization rates, good patient-reported outcomes and patient-reported experience. Bundled payments, personal health budgets and pay-for-coordination models are policy solutions which move towards this direction (NHS, 2023a; Pennestrì, 2021; Pennestrì, 2017; Pennestrì & Banfi, 2022). Training health and social care professionals on team cooperation and communication can also improve effectiveness, efficiency and soft skills (Pennestrì *et al.*, 2023).

At the tariff level, room for improvement is expected by the adoption of out-of-pocket payment exemptions based on age, income or clinical vulnerability (i.e., age over 65, income under a certain threshold, presence of chronic disease). Comprehensive care coverage should be provided by the care manager and monitored by the patient's case manager to make sure that the entire pathway is sustainable for the patient. Investments in formal home care can be beneficial for patients who a) are not safe at home alone, b) do not require high-technology hospital care, c) cannot afford a residential care bill. Gradual rehabilitation programs like restorative care and reablement are being experimented, for this purpose, in the UK. In Italy, integrated home care investments have been required by the National Recovery and Resilience Plan (Cochrane *et al.*, 2016; Ministerial Decree 77/2022). Telemedicine can also work to monitor ordinary parameters and provide consultations directly at home (Pennestrì & Banfi, 2023).

Chronic care management and intermediate care development are expected to improve communication issues as well, by following the patient throughout the entire health journey, planning post-acute care or rehabilitation in advance, taking contact with the reference professionals and investigating whether the patient has someone to lean on outside the hospital.

At the layout level, great value can be unlocked by involving users in designing the facilities they are dedicated, either by assuming their perspective through the opinion of patient associations, or by collecting patient-reported experiences. Sometimes a simple path on the floor, additional benches or clear toilet indications can make the ordinary attendance of health care facilities easier. In terms of time, outpatient visits are being scheduled at evening, in the Region of Lombardy, to meet the needs of working care givers and reduce waiting lists (Quotidiano Sanità, 2022).

Social prescribing is a another worth-mentioning strategy to maintain older adults busy, motivated and close to the context they live in, for free (Jani, 2020). Social prescribing, also known as community referral, is a means of enabling health professionals to refer people to a range of local non-clinical services. It is an approach that connects people to activities, groups, and services in their community to meet the practical, social and emotional needs that affect their health and wellbeing (NHS, 2023b). The referrals are generally prescribed by primary care professionals like GPs or practice nurses. Examples of social prescribing activities are volunteering, arts activities, group learning, gardening, befriending, cookery, healthy eating advice and sports (Buck & Ewbank, 2020). Although social prescribing is an all-age approach, it should suit older adults particularly well, for the eligibility criteria are having one or more long term conditions; needing support with low level mental health issues; being lonely or isolated; having complex social needs which affect their wellbeing (NHS, 2023b). The Region of Campania, in Italy, has experimented the transmission of craft techniques from lonely older adults to young people eager to learn, giving meaning to the days of the former, teaching the latter a job for free, and keeping local traditions alive over time (Pennestrì et al., 2022).

Social prescribing is a form of primary prevention, to the extent it maintains a beneficial lifestyle for physical activity and cognition, compatibly with age; it is a form of secondary prevention, to the extent it keeps the elderly surrounded by people who can see whether they have some latent or minimal health deterioration they may not be aware of, and recommend to see a doctor to prevent complications; it is a form tertiary prevention, to the extent it prevents isolation and inactivity to worsen chronic health conditions. According to Jani *et al.* (2019), a social prescriptions formulary should bring social prescribing on a par with drug prescribing.

5. Conclusions

Appropriate organization of care can help older patients cope with chronic morbidities and social isolation, reduce inappropriate medicalization and improve quality of life. The stimulation of social activity can delay functional deterioration, improve autonomy and help them maintain a meaningful existence. On the one side, solidaristic healthcare systems are more and more unsustainable. On the other side, they largely rely on medicine as the only solution for maintaining acceptable health. A more holistic approach can be beneficial for older adults. Medicine does not have to be holistic. Holistic must be the system that combines medicine with other types of care and support (e.g., societal, psychological, spiritual), when these types of care are equally or more functional to maintaining or improving a person's wellbeing. Before denying care to older adults or giving them lower priority, the care they are dedicated should be rearranged to fit better with their peculiar needs. The ability of solidaristic systems to understand and implement these indications will be evaluated over time.

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