The Role of Citizenship, Culture and Voluntary Community Organisations towards Patient Empowerment in England and Greece

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Abstract

Background: Comparison of the development or evolution of patient empowerment across different health systems, can illuminate similarities and differences, providing evidence for improvement and reform.
Aims: To compare the historical evolution of citizenship, culture and voluntary community organisations that may have shaped expectations and meanings of patient empowerment in England and Greece.
Methodology: A critical review of relevant historical, research and policy literature in English and Greek language.
Results: Diverse social and historical factors have affected citizenship, being strong and expanded in England and weaker with strong social determinants in Greece. Powerful intermediary bodies, with long tradition of voluntary health action, have been developed in England; whilst in Greece an absence of strong intermediary and generic health related organisations resulted in a more recent history of voluntary action and increasing actions on patients' rights.
Conclusion: Patient empowerment expectations and meanings as shaped by citizenship, culture and voluntary community organisations have been developed and expressed differently in these countries. These may have affected the development of patient empowerment systems, structures and services.

Keywords: patient empowerment; patient involvement, patient rights; England; Greece; citizenship, culture, voluntary community organisations

Introduction

Empowerment and engagement are goals of a global strategy on the achievement of integrated, people-centred health services between 2016-2026 (WHO, 2015), following recognition of patient empowerment (PE) and its benefits (WHO, 1986 and 1997; COM, 2007; WHO, 2008; All Parliamentary Groups on Global Health, 2014;

WHO, 2015). The *Tallinn Charter* recognized the importance of making health systems more responsive to patients' needs, preferences and expectations, committing WHO Member States in Europe to strengthening health systems (WHO, 2008). The European Community White Paper for 2008/2013 recognized citizens' rights to be empowered in relation to health and healthcare,

through community health policies taking rights as a starting point, encompassing participation and influence on decision-making and competences needed for wellbeing, including *'health literacy'* (COM, 2007). The value of patient engagement and empowerment has also been discussed in international forums, bringing forward proposals for strengthening national approaches to patient engagement and the advocacy capacity of patients (IAPO, 2010). Recently, WHO called for action on PE (WHO, 2013), recognising that patient, family and community engagement are assets for building capacity and quality of care (WHO, 2014).

England and Greece represent two distinct health and welfare systems (WHO, 2005; Economou, 2010; Healthcare Economist, 2008; Tanner, 2008; Wendt, 2009). These countries, which have not been compared in relation to empowerment before, belong to the European Union; thus, they share common European policies, standards and targets in various areas, including health (COM, 2000 and 2006; WHO, 2008). Both are engaged in professional, political and public discussions about patient empowerment. In addition, both countries have recognised the benefits of making health systems more patient-centred and responsive by adopting patient empowerment strategies (Busse et al, 2008). Comparison of PE across two different health and welfare systems can illuminate similarities and differences, providing evidence for improvement and reform (Ovretveit, 1998). For both countries, comparative research could be beneficial in building connections and relationships, help to bridge the gap between research and policy implementation and contribute to wider European developments (COM, 2000 and 2006).

Research questions and aims

The term *'patient empowerment'* (PE) is used as an inclusive term here, encompassing different levels, strategies, methods and dimensions of involvement/participation, including patient involvement and patients' rights across-countries. It refers to all mechanisms enabling patients to gain control and make choices in their health and health interventions (O'Cathain et al, 2005), the act or process of conferring authority, ability or control (Farrel and Gilbert, 1996). More choice, more information, more personalised care may be

elements leading to real empowerment of patients to improve their health. There are many concepts and definitions relating to PE, including patient and public involvement (PPI) and patients' rights *(Table 1)*. These have been discussed elsewhere and this paper does not aim to engage in such discussions (Bryne, 2004; Farrel and Gilbert, 1996; Kelson, 1997; Mackenney and Fallberg, 2004; O'Cathain et al, 2005).

A developing consensus recognises that PE is increasingly important to health governance, resulting in better systems responsiveness to health consumer's views, preferences and self-management of health. However, a number of key patient empowerment questions remain unanswered in both England and Greece. For example, the implementation of patient empowerment, expressed as PPI or patient rights' systems and cultures may be influenced by external national factors such as citizenship, general societal culture, and the influence and actions of voluntary and community organisations (VCOs). This paper aims to compare the historical evolution of citizenship, culture and VCOs that may have shaped expectations and meanings of patient empowerment in England and Greece

Methodology

A wide-ranging critical literature and policy review using a structured approach was undertaken. English and Greek language policy, theoretical, research and discussion papers were identified, summarised and critically appraised. The review was conducted between April-December 2006, revisited in January 2012-June 2013 and again in August-September 2015. Combination of the following terms: 'patient empowerment', 'patient (and public) involvement', 'patients' rights', 'health policy', 'citizenship', 'culture', 'voluntary community organisations', 'community participation' were searched, using different databases, search engines and websites:

• electronic databases in medical science, i.e. Medline; in nursing i.e. CINAHL; social and other sciences, i.e. PsychINFO;

• Greek medical databases, i.e. Iatrotek.org, MedNet.gr;

• other related electronic websites i.e. King's Fund, Picker Institute Europe, World Health

Organisation, Greek National Centre for Social Research (Εθνικό Κέντρο Κοινωνικών Ερευνών - EKKE), Greek National Documentation Centre (Εθνικό Κέντρο Τεκμηρίωσης);

- specific journal electronic searches, i.e. Health Expectations, Health Service Journal, The Greek Review of Social Research (Επιθεώρηση Κοινωνικών Ερευνών), Archives of Hellenic Medicine;

- the websites of the Department of Health in England, the Ministry for Health and Social Solidarity in Greece, and NHSs in both countries;

- grey and non-grey literature produced by voluntary and community organisations, identified through personal links and conferences;

- email alerts, links and memberships of relevant bodies and organisations, i.e. Patient Information Forum.

Results

Citizenship and culture

England

Three periods in the evolution of citizenship witnessed the acquisition of civil, political, social rights and duties (Marshall, 1950; Heater, 2004).

The 17th – mid-19th centuries were characterised by engagement in social and economic activities, from the freedoms to own property and goods exchange to liberties of thought and choice of church. Subsequently, the end of 18th - start of 20th centuries was characterised by gaining political rights to vote and stand for election. Finally, the mid-20th century saw the creation of social rights, from '*the right to economic welfare and security*' to '*the right to share to the full in social heritage*' evolving to include social insurance against unemployment or illness, rights to education, healthcare and pensions.

Colonialism, industrial revolution, liberalism, imperialism may have bred a sense of belonging, loyalty, unity and pride, as well as *an interest in the collective good, community spirit and volunteering* (Firth, 2007 and 2009) *(Table 2)*.

In the 19th - 20th centuries, citizens formed associations and organisations for collective action, transforming individual into group demands,

influencing political parties, government and policy-making processes (Legg and Roberts, 1997).

This '*social participation*' is rooted in traditions of informal self-help, solidarity, mutual aid, more organised associations providing help to members aligned with philanthropy and voluntary service, improving lives of the '*less fortunate*' (Brodie et al, 2009).

More recently, structures have sought to promote '*community participation*' in health governance (i.e. Foundation Hospital Boards), leading to better, more responsive services, tackling citizens disengagement from politics and the democratic process, building social capital (Skidmore, Bound and Lownsbrough, 2006).

Greece

Plato and Aristotle first discussed *ideal state, citizenship and its principles* in 4th and 3rd century BC Greece (Heater, 2004; Bellamy, 2008).

Later Byzantine '*patrimonial*' political domination and Ottoman '*sultanist*' power, together with familial social organisation and economic production, diminished the possibility of a contractual idea of citizenship (Demertzis, 1997), stifling its development (Makridimitris, 1999) and together with the power of Christian Orthodoxy, exerting major long-term effects.

Consequently, *atrophic civil society and lack of contractual citizenship* has resulted in absence of strong intermediary bodies between the state and the quasi-capitalist market, whilst the family is a central institution of social, economic and cultural reproduction (Demertzis, 1997; Makridimitris, 1999; Davaki and Mossialos, 2005)

In the 19th and 20th centuries, revolutions, dynastic change, oscillation between constitutional monarchy and republic, military coups, general government and political instability, set the country apart from other Western European states.

Dominating educational, cultural, political and economic influences of the '*great powers*', i.e. ex-Soviet Union, UK, France, Germany and USA, as well as EU funding and its recent channelling, further cultivated *clientism* and '*patron-client*' relations, affecting the notion of citizenship (Economou, 2010). Consequently, Greeks are not

used to voluntarily joining broader groups for collective action and existing intermediary bodies are viewed with suspicion (Legg and Roberts, 1997; Michailidou, 2005).

Modern Greek culture and attitudes related to the atrophic civil society encompass reliance on family and interpersonal relationships, instrumental attitudes towards law, distrust of impersonal authority, a concern for public affairs arising out of the need to serve private interests (Michailidou, 2005). An '*irresponsible individualism*' and an '*obsession with power politics*' were also suggested (Kioukias, 1993).

The role of VCOs

England

VCOs have improved the effectiveness of certain norms and reinforced coordinated action, contributing to information and communication between parties, reducing relevant economic and social costs, forming vehicles for better policies, financial and social collaborations (Puntman, 1992). A history of voluntary action in health and welfare exists, i.e. the UK's oldest teaching hospitals were originally voluntary hospitals funded by wealthy patron's subscriptions.

Subsequent forms of voluntary activity provided complementary or ancillary services to statutory provision, pioneering innovative service delivery, especially to those not well-served by the mainstream. Some organisations ensured availability and appropriateness of services related to needs of users/members rather than delivering services directly; others engaged in preventative activities, addressing wider socioeconomic determinants of health.

Recently, VCOs campaigned, lobbied and advocated on behalf of health service users, for greater decision-making involvement and better quality healthcare. Making patient care a matter of public concern, they promoted greater choice of services, giving people a louder voice to influence decisions, enabling informed choices, providing support for intervention, working to address

inequalities. The Patients Association, established in the 1960s (2005), followed by other generic organisations, i.e. the Patients Forum in the 1980s (2012), voiced patients and carers' concerns on treatment, care, and services delivery. Condition-specific organisations, i.e. Mind, Age Concern, Sign, Stroke Association, also voiced patients' concerns, influencing national policy directions. In many areas, voluntary bodies became national expertise centres; it was eventually recognised that users may command more information than professionals, with the notion of the '*expert patient*' (Appleby, Harrison and Devlin, 2003).

Thus, PE evolved and resulted partly from VCOs challenging services to be patient-centred (DH, 2009). Current policy strongly supports creation of a mixed economy in healthcare, encouraging a wider range of providers, including VCOs, to deliver services on behalf of the NHS, removing barriers preventing them taking an expanded delivery role (DH, 2008) and working innovatively to engage communities (NHS England, 2014). *(Table 3)*

Greece

Only a small number of mediating institutions, interest groups, societies or non-profit organisations could reflect the atrophic society (Kioukias, 1993; Polyzoidis, 2006). The state has subsumed an enormous range of responsibilities; its interests superseding individual civil and political rights. Since inception of the modern Greek state (1821), VCOs, mostly related to the Greek orthodox church, have actively assisted the poor and socially disadvantaged financially and practically. However, the cholera epidemic in 1954 reinforced establishment of more formal VCOs to support those affected (Polyzoidis, 2006).

In psychiatric care, volunteering first appeared as philanthropic action by wealthy Greeks (1830-1914); further groups supporting the liberal definition of philanthropy became involved later (1914-1950). Subsequently, volunteering connected with advocacy organisations and the new social movement (1950-1983).

Table 1. Patient empowerment concepts and definitions

Concept	Definitions
Patient empowerment (PE)	Inclusive term, encompassing different levels, strategies, methods and dimensions of involvement/participation, including patient involvement and patients' rights across-countries.
	Refers to all mechanisms enabling patients to gain control and make choices on their health and health interventions; the act or process of conferring authority, ability or control (O'Cathain et l, 2005; Farrel and Gilbert, 1996).
Patient involvement (PI) or patient and public involvement (PPI)	*Patient involvement' (PI)* or *patient and public involvement (PPI),* a term commonly used in England- refers to active participation of patients/carers -and the public-, as partners in their own care and treatment at various levels, i.e. health services planning, service delivery, quality monitoring, development (Kelson, 1997).
Patients' rights	Patients' rights, entitlements and duties, are what citizens can expect of health systems and providers of care, and what is expected from them (Bryne, 2004).
	Fundamental rights are those for information and complaining. Respect for the individual citizen's *'voice'* and *'choice'* are the underpinning values of all rights (Mackenney and Fallberg, 2004).
Citizenship	Citizenship refers to the status of being a citizen, a member of a particular political community or state. Citizenship also refers to involvement in public life and affairs, to the behaviour and actions of citizens. Finally, it also refers to the process of helping people learn how to become active, informed and responsible citizens (Firth, 2009).
Culture	The way of life, especially the general customs and beliefs, of a particular group of people at a particular time; overarching characteristics of people, i.e. in England or in Greece, shaped by historical and other reasons. (Cambridge English Dictionary, 2015)

Table 2. Citizenship and culture towards patient empowerment

	England	Greece
Elements	**Citizenship and Culture**	
Evolution of citizenship		
- 4th and 3rd Century BC		Ideal state, citizenship and its principles
- 12th - 20th Century	17th - 19th Century: Engagement in social and economic activities	12th - 18th Century: Diminished contractual idea of citizenship
	18th – start of 20th: Gaining political rights to vote and stand for election	19-20th Century: Clientism and 'patron-client' relationships
- 20th Century	Mid-20 Century: Creation of social rights, right to healthcare, interest in the collective good and community spirit	Not used to broader groups for collective action
	Expanded role	Weak role (atrophic civil society)
Intermediary bodies/mediating institutions	Strong political parties, interest groups, cooperatives or union	Absence of strong intermediary bodies between state and the market
	Associations and organisations for collective action, 'social participation', 'community participation'	Not used to broader groups for collective action; intermediary bodies are viewed with suspicion
Tradition of participation/engagement	Long tradition of social and community participation	Clientism
		Central institution of family in social, economic and cultural reproduction

Table 3. Voluntary community organisations towards patient empowerment

History in health	Long history	Recent history
Range/roles of voluntary community organisations	Wide range: campaigning, lobbying, advocating for health service users	Narrower range but expanding due to increased awareness of patients' rights
	Important role in patient empowerment/patient and public involvement since 1960s – they are seen as national expertise centres	Historical role related to orthodox church, mostly in social and psychiatric care
	Generic and condition-specific organisations	No generic organisations; increasing recent activity of condition-specific organisations
Impact of voluntary community organisations	Patient empowerment/patient and public involvement evolved and resulted partly from their actions	Their impact is increasing based on patients' rights: 1990s and more recently due to economic and social crisis
	Creation of a mixed economy in healthcare, including voluntary community organisations	State retains an enormous range of responsibilities

Since 1983, non-profit and non-governmental organisations have answered demands for psychiatric reform, striving to express civil society and be included in the official Greek welfare system (Bilanakis, 2008). VCOs representing patients with other conditions, aiming to improve health services developed mostly in the early 1990s, although activities were initially limited (Michailidou, 2005). During this period, public awareness of patients' rights increased, marked by publications and discussions amongst healthcare professional associations, patient organisations and politicians (Merakou and Tragakes, 1999).

More recently, VCOs have centred on problem-specific resolution, acting as pressure groups (Polyzoidis, 2006) *(Table 3)*. Forty-two VCOs assisting people with disabilities and illnesses, through financial support, counselling, advisory or legal assistance, health recovery, prevention and awareness, were identified in 2004 (Polyzoidis, 2006). There are national disease-specific organisatitions, i.e. Hellenic Cancer Society, Diabetes Association, but few serve generic patients or health care purposes (Fothnet, 2006). A generic Health Services Users' Network, to protect public/private service users' rights and improve health services' quality was established in 2001 (now disestablished) (Kouris, 2001). The current Greek economic crisis has resulted in establishment of many VCOs supporting those with health and social care needs, raising numbers to ninety-eight in 2015, i.e. Emphasis, Xamogelo tou Paidiou (Directory 11888, 2015; MoH, 2015).

Discussion

This is the first paper to compare the historical evolution or development of citizenship, culture and VCOs towards patient empowerment in England and Greece. Non-withstanding its limitations, i.e. based only on critical literature and policy review in English and Greek language, it has highlighted important differences and similarities.

Diverse social and historical factors, citizenship, cultures and VCOs were identified in the two countries *(Tables 2 and 3)*. In England the role of citizenship is strong, expanded, with intermediary bodies, and marked by a culture of social and community participation. Consequently, the VCOs' range is wide, encompassing generic and condition-specific organizations, impacting positively on PE development (Legg and Roberts, 1997; Brodie et al, 2009). In contrast, in Greece the role of citizenship is weaker, intermediary bodies are absent and participation has been constrained by atrophic society. Although there are no generic VCOs, social determinants are strong, and awareness of patients' rights, actions on rights and economic factors are contributing towards more condition-specific VCOs more recently (Demertzis, 1997; Makridimitris, 1999; Davaki and Mossialos, 2005; Economou, 2010; Polyzoidis, 2006). Currently, VCOs act as pressure groups influencing policy and reform in both countries, but in England their expanded delivery role has stemmed from recognition that a mixed economy in healthcare is desirable, efficient and empowering. Although collaboration between hospitals and non-profit organizations was endorsed in Greek legislation in 2005 (Greek Parliament, 2005) and VCOs activity has been increased with the economic and social crisis most recently (Directory 11888, 2015; MoH, 2015), further evolution of the VCOs' role regarding a mixed healthcare economy could lead to the development of more generic VCOs with increased financial, empowerment and health benefits.

It is acknowledged that the two countries have different health and welfare systems, patient empowerment -PPI or patients' rights- national policies, systems and development. England has a centralised, comprehensive health system with mainly public delivery of services, characterised by a medium level of total health expenditure (Healthcare Economist, 2008; Tanner, 2008; Wendt, 2009); while Greece has a public-private mixed for both funding and delivery system, characterised by high out-of-pockets payments (WHO, 2005; Tanner, 2008; Wendt, 2009; Economou, 2010). It has been discussed elsewhere that the Greek welfare system -and arguably the South European model- has important particularities, i.e. the persistence of clientelism, the lack of efficient, rational administration and the weakness of the civil society (Demertzis, 1997; Makridimitris, 1999; Economou, 2010) together with the central social, economic and cultural role of the family (Davaki and Mossialos, 2005; Polizoidis, 2006). The English welfare system -or

Anglo-Saxon model, on the other hand, focuses on efficiency, quality, low level of expenditures and social assistance of last resort, but arguably less equity (Tanner, 2008; Firth, 2009). The interrelationships between health systems, health, wealth and societal well-being have been recognised (WHO, 2008). All these may also contribute to patient empowerment, in terms of access and provision of information, gaining control, making choices, personalised care and more participatory and inclusive services (Farrel and Gilbert, 1996).

Conclusion

Diverse historical, social and political factors have affected the evolution of citizenship and cultures of empowerment in both countries. In England, the strong and expanded role of citizenship, marked by a culture of community participation and VCOs, may have impacted positively on PE development (Legg and Roberts, 1997; Brodie et al, 2009). In contrast, in Greece the weaker role of citizenship, atrophic society with constrained participation and VCOs, may have limited PE development.

Policy makers may want to consider these factors in the development and implementation of national or international policies to achieve global PE targets. In both countries achievements have been made in recognizing benefits of patient-centred health care by adopting PE strategies. Achieving global strategies' aspirations for integrated patient-centred services require challenges to be met regarding effectiveness of policy implementation in both countries. Future studies could draw on these findings and explore how the local/national context and settings may influence patient empowerment within organisations, i.e. hospitals, with the implementation of the patient empowerment policies and legislation. For both countries, comparative research could be beneficial in building connections and relationships, help to bridge the gap between research and policy implementation and contribute to wider European and international developments.

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