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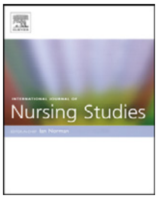

# The ethics and politics of home care

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ABSTRACT

*Background:* In the dominant health-care policy, commonly referred to as New Public Management, primary emphasis is placed on the reduction of costs in health care. This development threatens to increase inequality in society based on levels of health or impairment and on gender.

*Aim:* The aim of this paper is therefore to raise awareness among nurses about the impact of New Public Management and explore how they might develop services that meet the diverse needs and wishes of those being served.

*Theoretical approach and method:* Although this policy has been criticised by nurses, it has also been observed that they are key players in its realisation. This discussion paper explores the impact of different discourses upon the practice of home-nursing care. It was developed within the post-structural tradition, where discourses are considered of key importance in shaping practice. Discourses represent different viewpoints and interests, and determine what can be considered meaningful and possible. The empirical studies which form the base for many of the main arguments presented were identified through an extensive review of published ethnographic research of home care in the years 2000–2008.

*Results:* A review of studies conducted in a number of countries both in North America and Europe showed that home-care services have in many ways been diminished. Clients and their caregivers experience insecurity and wish for more assistance. With New Public Management the focus has shifted from an ethical discourse to an economic one, although this shift has not been clearly articulated and critiqued. By understanding the impact of New Public Management, nurses can better focus their practice to meet the diverse needs of patients and their caregivers.

*Conclusion:* In order to be able to respond to retrenchment in health services, nurses need to understand the complex ethical and political issues of New Public Management. A number of practices can be developed for working with patients and their families in such a way that their needs and wishes are respected.

**What is already known about the topic?**

The impact of the retrenchment of welfare services upon patients and their families has been discussed extensively in the nursing literature and elsewhere. Nurses have identified numerous examples where such cuts have had a negative impact.

**What this paper adds**

This paper clarifies the ethical issues that emerge as a result of the shift in the discourses about health-care services towards a predominantly economic discourse. By re-visiting ethical discourses on health services as an entitlement, and by clarifying the gendered nature of the issues under consideration, my aim is to help nurses clarify their ethical and political understanding of home-care nursing. By enhancing such an understanding we can better envision how home-care practice can meet the needs of those being served.

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## 1. Introduction

In most countries policy on health-care services has in recent years focussed on ways to contain costs. This policy has been implemented through a number of approaches such as rationing of services, outsourcing and privatisation (Cartier, 2003). The location of the provision of care has been shifted from institutions to the home. Patient self-care is encouraged, and the family is identified as central in providing assistance to people with long-term illnesses or a decreased ability to care for themselves. At the same time, services that have traditionally been regarded as health care have been redefined as social matters belonging to the private sphere of the family (Simms, 2003). This trend indicates a fundamental shift in the understanding of the relationship between citizens and the state, from a collective responsibility for the well-being of nations, embedded in the idea of the welfare state, to a private responsibility of individuals and families. As a result of this redefinition, responsibility for comprehensive health and social services will shift, and in many ways has already done so, from the state to the family (Björnsdóttir, 2002; Jenson and Jacobzone, 2000; Levine, 1999a,b; McKeever, 1996). This paper will analyse the impact of this policy on the lives of those who need assistance at home, their caregivers and the practice of home-care nursing.

There are considerable indications that, as a result of the policy described above, some groups of patients, particularly the frail elderly and people with long-term illnesses, who live in their own homes, feel abandoned by the public health-care system (Aronson, 2002; Aronson, 2006; Ceci, 2006a; Janlöv et al., 2006; Purkis, 2001). Similarly, numerous studies have described the burden, stress and failing health experienced by relatives who have become family carers in the home. In many countries, carers have joined together in associations aimed at providing support to caregivers and lobby for public assistance. These associations regularly publish statistics related to family caregiving, which indicate that many caregivers are under considerable stress and feel burdened by their responsibilities (NAC and AARP, 2004; Fast and Keating, 2000). In addition to the physical and emotional difficulties experienced by carers, many of them endure financial hardship (Carers, 2007a,b; Gibson and Houser, 2007). From these facts it may be inferred that the policy described above has increased inequality between people with long-term illness and the frail elderly and those who do not face such difficulties.

In most societies family caregiving has traditionally been the responsibility of women, either as unpaid relatives who provide assistance based on obligation or love for the person needing help, or as part of public services provided by the state or municipalities. There are also considerable gender patterns in the extent to which individuals feel themselves responsible for the well-being of others, in the structures of the labour market and even in citizenship rights (Sevenhuijsen, 2000). Although men certainly participate in informal care, studies repeatedly find that the overwhelming majority of caregivers are women. Therefore, in a world that is still shaped by traditional views of women's nature and sphere of activities, the development outlined above may have particularly serious consequences for them, perpetuating gender inequality and the vulnerability of women (Armstrong, 1995; Jenson and Sineau, 2001).

This situation constitutes a difficult dilemma for nurses working in home care. Home-care nursing is performed in the space between public services and the home, and nurses become mediators between the private world of the family and the state or communities. Based on her study of home-care nursing in Western Canada, Purkis (2001) described how the nurses had been co-opted into limiting services to certain groups of patients, primarily those suffering from long-term illness. The patients were expected to manage their illness on their own. As a result of new managerial technologies aimed at limiting health-care expenditure, much of the work previously performed by nurses had been rendered invisible and therefore obsolete. These technologies were both overt rules, such as limits on the number of visits or length of services made available, and covert strategies that encouraged the nurses to stress patient independence and self-care. As Purkis observed, the attention of the nurses in the health-care units where the study took place had been diverted to a set of issues that they were allowed to work with. Other issues, which for example involved serious existential questions, were on the other hand left unaddressed. As a result of this, no time was allocated for finding out how the patients perceived their situation and what support they might wish to receive from the governmental sector. In light of her findings, Purkis called for an analysis of the politics of home-nursing care, suggesting that nurses might seek to reintegrate ethics into their practice by paying attention to the local knowledge of patients and caregivers:

> Home-care nursing practice might be reconceptualised as a political practice; a political practice that addresses *problems* encountered by people as their life concerns are more and more excluded as legitimately requiring support and assistance within the context of their home (Purkis, 2001, p. 149).

This paper aims to develop the kind of analysis called for by Purkis (2001). Although nurses' ability to help is often constrained by institutional regulations, it is imperative that the profession has a clear understanding of the aims, ideas and values that shape policy and how that policy impacts on the lives of those who need services. I will begin this paper by outlining the theoretical background and the method used in developing and substantiating the arguments made. I will then present a review of studies that have explored the impact on patients and their caregivers of the above policy, variously referred to as cutbacks, downsizing or retrenchment in the public health-care sector. In the process I will highlight the ethical and political issues that nurses working in home-care are confronted with in their practice as a result of the changes described above. I will then explore the way in which welfare services have been understood and conceptualised as an entitlement or a social right, and how such an understanding has facilitated gender equality. In the final