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Perspectives on Care at Home for Older People

Edited by
Christine Ceci, Kristín Björnsdóttir
and Mary Ellen Purkis



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Nothing should be more expected than old age: nothing is more unforeseen.

—Simone de Beauvoir, *The Coming of Age*

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Foreword

Illness is a Plural—Home Care, Governmentality and Reframing the Work of Patienthood

Carl May

Editors' note: Professor May's welcome contribution to this book is, uncharacteristically for a foreword, not a comment on the book itself or its contents. Rather it takes the role of context setting. Almost simultaneous with our initial meetings to determine the shape of this project, the editors of this book, as well as several of the contributors, participated in a conference¹ where Dr. May delivered a plenary address, *Agency, Prudence, Expertise and Resourcefulness: Sickness Work in the 21st Century*. In this talk he sketched out certain of the forces—including epidemiological and demographic transitions—influencing current trends in the organization and delivery of health care in advanced economies and described the effects of these changes in terms of a shift in the burden of the work of illness care from providers to patients. There is, he suggested, a “wholesale re-arrangement of the work of being sick” and we ignore these structural shifts at our “peril.” Well, we thought, a shifting burden of work also describes much of what we see for the older people with whom we are specifically concerned—there is also ‘work’ involved in being old, being frail, in needing care—and we need to be carefully attending to the way in which this is occurring. So in a sense, Dr. May sets out, in this foreword but more extensively in his other work, the problematic with which each contributor to this book grapples—the conditions of possibility for good care. (CC, KB, MEP)

Underpinning many current debates in health care is the sense that health care is at a crossroads, and that this crossroads defines more than the problems of demography and costs that policy makers—on both sides of the Atlantic—sometimes seek to make the focus of our attention. Indeed, the current healthcare crisis can be characterized as the price that the advanced economies must pay for successfully overwhelming the mass of infectious and acute disease that winnowed their populations until the mid-twentieth century (Holman 2006). Nevertheless, in those same advanced economies these successes are infrequently celebrated by policy-makers, who see in place of those winnowed generations an ever-growing cohort of older

people with multiple chronic co-morbidities, who require care over lifetime illness careers, in place of cure for episodes of acute disease. The policy problem is therefore composed of a set of anxieties about the management of increasingly scarce healthcare resources, in the face of ever-growing demands. There is a sub-text to this, too. It is that sick older people are a problem because they subtract tax-dollars from the interests of younger healthy people.

In the face of these shifts, health-care researchers are often pressed to see their task as contributing to the management of scarcity (perhaps by finding rational and ethical bases for rationing and for the withdrawal of care), and to respond to this continually growing demand on social resources by finding technological fixes for it (perhaps by redirecting it into new professional or organizational systems of practice). Governmentality in contemporary healthcare is expressed, therefore, in patterns of technogovernance at the micro-scale (May et al. 2006), and in the reformulation of professional-patient relations through incremental bureaucratization and the corporate impulses of healthcare providers at the macro-scale (May 2007). In this short essay, I want to make three claims about the effects of these processes on the practices of healthcare and speak to the necessity of theory through which these effects can be defined and interpreted.

Our starting point must be the traditional way of thinking about patient-hood, in which the patient is assigned a role in relation to clinical practices and their contexts. Whether we see this *relation to* in terms of a very passive role or, at the other end of the spectrum, as a very active consumer of healthcare, this is a view that relies on the application of old asymmetries of power and knowledge. This is equally true of both the Parsonian assumptions underpinning 'sick role' theory (Parsons 1951, 1975) and of more recent postmodern accounts (Fox 1993; Morris 1998). Here, psyche and soma are objects to be measured and manipulated through interactions with medical knowledge and practice. But as treatments become ever more complex, and the burden of labor and time that they present to patients becomes more demanding, we need to think about the divisions between professionals and patients, between the healthy and the sick, and the sick and their significant others. This is because of the increasing burden of technical expertise, self-monitoring, self-care and routine symptom management, record-keeping and the accumulation of information, and organizational and coordinating labor that is being shifted from the clinic into the home (May 2009). Here the population of individualized patients provides an insufficient workforce to perform the business of healthcare; work has to be further distributed to family and friends as new machines are incorporated into the home, web-interfaces opened up, and telecare systems operationalized. We can find a generative principle of the emergent forms of home care at work here:

The patient is not enough.

(The burden of illness now demands more than a co-operative patient, instead it requires a compliant network.)

If the patient is not enough for healthcare systems, then the work of self-care and healthcare is an ever-expanding universe of labor. Parsons (1965) argued that we should see sickness as a “job of work” and that is precisely what it has come to be. While older people with multiple chronic co-morbidities are claimed to be a drain on resources and a brake on national economic competitiveness, they too are drained, as substantial burdens of work are shifted to them.

Of course, the work of sickness has permeable boundaries, multiple contingencies of practice, and it radically alters biographies and identities (Bury 1982; Charmaz 2006). One way of seeing this problem has been, from the earliest days of social science analysis, by applying the notion of *illness career*. Chronic illnesses are managed and modified over lifetime trajectories. They ebb and flow, suffer instabilities and exacerbations, but are equally frequently experienced as the constant and barely changing background radiation of a limiting universe. If we think again about the experience as illness, we can see these careers not as evidence of the inevitable failure of the body, but as a series of episodes of sickness engaged with implementation projects, in which different assemblages of actors and actants—drawn out of multiple territories and trajectories—are committed to the business of care. These projects multiply the possibilities of treatment and add steadily to its burden because they fragment experiences of care and threaten the individualization of patient care upon which many of the claims of professional ideologies rest. This leads us to a second generative principle:

Illness is a plural.

(In a world defined by multiple chronic co-morbidities, sickness is experienced as an assemblage of management projects rather than a phenomenological unity.)

Now, the spatial and temporal fragmentation of care means that relations between sick people and the sources of their care are often unstable and emergent, not simply because of the regularities of titration, but because of changing constructs of evidence and the timetabling of careers and credentials. We therefore need *minimally disruptive* healthcare and to consider the burden of illness in relation to the burdens and incivilities imposed on people by the proliferation and expansion of treatments, and fragmented and uncoordinated patterns in the delivery of care (May et al. 2009b). The practices of self-care, home care, and formally defined professional care are organized, increasingly, around the multiplication of coordinating activity. This takes us to a third generative principle.

*The co-ordination of co-ordination is not a paradox.**(The multiplication of co-ordination gives recognition to the complexity of contemporary healthcare.)*

In these contexts the *home* as the center of home care is no longer a bounded domestic territory, but is now a suburb of the healthcare system itself. It has organizational significance as a place to which clinically defined work can be relocated, and it is this—rather than any ideological or ethical impulse—that gives truth to the claim that patients are partners in their care. *Of course* patients are ‘involved’ in their care. They and their significant others are enrolled as unpaid workers in these extended and extending systems of practice. They contribute not only practice (doing or not doing what they are asked by health professionals), but by building a body of technical expertise that is circulated through epistemological communities that exist in parallel to, and sometimes competition with, the repositories of clinical knowledge and practice to which they are supposed to defer.

Because of the empirical shifts that I have sketched out above, we can now dispose of two analytic conventions. First, that accounting for experiences of illness and its meanings—and the biographical disruptions that stem from it—means that our analytic narratives must be primarily focused on the phenomenology of sickness. Second, that accounts of experiences of illness are an adequate response to the assumption of scarcity and the problem of rationing. The phenomenology of illness and the problem of scarcity are, it seems, united by the work that sick people and their others do to stay on top of their symptoms, to stay engaged with their treatments, and to co-ordinate and manage the combined burdens of illness and care. Theories of socio-technical change have a good deal to offer us as we attempt to understand the shift to home care because they refuse to divide the social and technical, and because they also refuse to play out the technical as either determined or determining. Home care is not the necessary outcome of cost control but is rather the product of multiple contingencies. It is one of a number of possible results of interactions between the ‘social’ and the ‘technical’, in part because this shift is an epiphenomenon of deeper and more fundamental changes in the way that healthcare systems themselves deal with the problems of coordinating coordination, of the plurality of illness and the inadequacy of patient-hood.

Where do the three generative principles that I have outlined above take us? One place that they might take us is into the domain of the *socio-technical* as it is outlined in Science and Technology Studies (Webster 2007). This is where I and my colleagues have been building theory that seeks to explain the how ‘innovations’ (defined broadly) are implemented, embedded and integrated in practice by healthcare providers—and the ways that the management of health technologies (again defined broadly) in practice is increasingly distributed (May and Finch 2009; May et al. 2009a). The point of emphasis here is that the more that we have examined the practices of healthcare technologies and organizations, the more we have observed the

collapsing boundaries between patient, carer, worker and professional. Their work is being redistributed within compliant networks. This redistribution parallels the collection and systematization of knowledge about the health of the self and assumes a diffuse (and increasingly, unpaid) labor force. In relation to which, assumptions about the ownership of knowledge and practice can be designed *out* of artifacts and systems, as well as designed *into* them.

NOTES

1. *Government of the self in the clinic and the community*, 3rd International In Sickness & In Health Conference, April 15–17, 2009, Victoria, British Columbia, Canada.

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Introduction

Home, Care, Practice—Changing Perspectives on Care at Home for Older People

Christine Ceci, Kristín Björnsdóttir and Mary Ellen Purkis

Conceiving of a thing is a fundamental kind of political activity.

—Alan Finlayson, 2006

Library shelves all over the Western world are heavily weighted with books that take up questions of the ‘problems’ of age and what should be done about it. Standing in front of these shelves can be not only intimidating but also a little bit disheartening. Row upon row of handbooks on age and ageing written for nurses, social workers, gerontologists, psychologists, sociologists and families going back decades. Books by and for researchers, academics, bureaucrats, practitioners and the general public. National surveys and outcomes research line up beside personal accounts, analyses of political and economic implications rest against organizational strategies for providing efficient services, assessments of the effects of health system restructuring crowd out guides intended to assist families to cope with their care ‘burden’. This ‘problem’—becoming old and what to do about that—has clearly, and for some time, preoccupied many. Surely by now everything critical, instructional or reflective has already been said. And yet it has not because, evidently, we still struggle with the question of how we want this to proceed, this caring for frail older adults in our societies.

This question of how to respond to the perceived challenges of ageing populations is very much on the policy and research agenda of many nations, and significant discussions are occurring concerning the place of formal home care, its possibilities and limitations, in meeting these challenges. Yet home care, as a formal practice, remains significantly under-theorized, with the meanings and assumptions shaping its key concepts—home, care and practice—rarely made explicit. Home care as such is assumed to require neither explanation nor analysis. Yet as a field of care, home care is made up of much that is materially and meaningfully heterogeneous. Discourses highlighting vulnerability, frailty or a decline associated with ageing run up against a rhetoric of self-reliance, responsibility and independence; those highlighting supply, demand and scarcity of resources push back against

claims of justice or entitlement—and vice versa. And the ‘field’ itself is contested, complex and dispersed, spread as it is across multiple, often hidden locations of activity (Baranek, Deber, and Williams 2004). A shift in the preferred site of care from hospital to people’s homes has implications for experiences of home and care and for the organization of the work itself. In many locations, there are disputes about the prioritization of different types of clients with different types of needs, concerns about resources spread too thinly, and apprehension about the effects of discourses of responsibilization and individualization and the growing influence of neo-liberal discourses in delimiting the role of the state. Yet in this mix and mess of discourses and practices, a complexity reflective of most areas of modern life, there remains, somewhere at home care’s core, the matter of concern of this practice—the enormously important questions people have about how they are going to be able to live their lives.

This collection is informed by this concern and framed by two central questions that examine the line currently taken around home-based supportive care and services for ‘frail’ older people. How do the actualities of people’s daily lives articulate with ideological, practical and programmatic discourses and material conditions? And what are the conditions of possibility for ‘care’ where the frailties of older people matter? And because in this collection we are most concerned with the organization of formal home care, within these central questions lurk many others: What is the state’s role in supporting those who are older and frail? What justifies or explains state involvement in or detachment from the ‘private’ life of citizens? These latter questions offer opportunities for thinking through not only what we mean by and require from the state but also, and reciprocally, how state-sponsored processes and practices function to constitute us as particular kinds of citizens. In some locations, Canada and the UK for example, it seems that it has become increasingly difficult to simply assert that people need to be cared for, a claim somewhat less contentious in the context of the Nordic welfare state—though here too, this ethic of care is changing. But increasingly, the argument must actually be made that those who are older and frail need help or assistance with various activities so they can lead a satisfying life. It seems that in these situations, where there are fewer clear links with the taken-for-granted constituents of appropriate health services, more convincing strategies of justification must be developed to support the provision of what comes to be called ‘social’ care, or care that helps people to hold on to the life they are living (see Ceci and Purkis 2011). This is a location of care that we think requires a more sustained theorizing: how are the boundaries between those who do and do not need help constituted and maintained?

The contributors to this collection write from a range of disciplinary backgrounds and geopolitical contexts demonstrating at the very least that home care is mediated by the settings in which it is enacted, with the particulars of practices shaped by local policies, priorities and resources.

International comparisons that theorize the social organization of home care bring to the fore deeply held views of what such help looks like and how it may be accomplished. As Kari Waerness (2005) argues, examining work that is contextual and descriptive contributes to understanding what is specific to providing good care. Attention to the specificity of diverse contexts also enables analysis of the ways that local social, economic and political systems and structures influence our views of the possible, and in so doing, enlarges these views. So though contributors to this volume do not develop prescriptions for practice, they articulate knowledge of the conditions of possibility for providing home care, that is, how current arrangements produce divisions among people, health and social care and the ways these are linked to a whole range of external influences and relations.

In Conversation¹ (1)

Davina Allen: So having done some critique of this business of home-based care, what can be done? I'm feeling like I want to be able to do something differently, and recognizing how problematic that is; like, is it possible? Just feeling like I can't stay here [with critique only] for too much longer, because it's just too uncomfortable. . . . So on what basis can I engage in that sort of writing or action with local health authorities or whomever to make these sorts of practices be more amenable and more sensitive and more permission granting. . . .

Mary Ellen Purkis: When I think about the paper I've written for this [meeting] and my interest in home care, and my interest in the kinds of questions Christine has raised for me about how do we want this to proceed, this kind of caring for frail older adults in our society, and I think about my parents as a sort of instance of that case . . . and the very brute force kind of way that we have to do this work seems so wrong against who these people are and what it might be that they're looking for. . . . In the literatures we are all most familiar with, is it the case that critiques have been undertaken, and then things have just been sort of left? So that we've got all of this—we've got this analysis of all the issues that face us, but there's not as much—okay, so what can we do about this now, what are the matters of concern. . . .

Sirpa Wrede: I think it would be very difficult for us as a group [to devise a programmatic intervention] . . . even though we would be *willing* to make a program for good care, I think we are coming from different contexts, we would be talking about different things when we would come down to the detail. . . . But I think what I've been getting from the

discussion so far is that what we share is a sense of the devaluation of care and the need to tackle that kind of analysis. We are trying to talk about normative issues without becoming programmatic . . . and yet I think that a risk of the use of the concept of care is that you tend to make the people objects of care and voiceless. . . . I think that perhaps we could try to think about frailty as a basis of social division, a way of othering and try to address how that takes place when we talk about care: how do we end up othering the older people who are in need of these services?

Joanna Latimer: One of the things that is so interesting about what you are saying is the idea that “we’ve got to go to the old,” because we are always thinking of it in this dyadic relation. I mean, they’re as much participants as anybody else. They may lie low and efface themselves but they’re still participating in particular kinds of practices and processes. So it’s not to give them voice; it’s the older person as a participant in this process . . . however, this idea of frailty, some think of frailty as something that inheres in persons, frailty and helplessness; but that’s a relational effect. . . . the minute you flip the world by saying that what frailty is is not just something that inheres in somebody because they can’t see, they can’t hear, they can’t walk. . . . It’s this relation between this body and the world in which they live, once you flip that over, you rescue the old immediately—they get rescued and brought back into play.

Sirpa Wrede: I think we need to think more about the concept of frailty somehow, I’m thinking of frailty as a social division that can be analyzed like other divisions such as gender. Not talking against how you are deconstructing frailty but holding on to the fact that it really is relevant in the way we talk about people. And I think a similar issue for me would be work, the position of home care work as devalued work is influenced by cultural understandings of old age . . . that is then how I go to the notion of power . . .

Christine Ceci: These are ideas that we have each committed to drawing through our papers, about practices and the effects of practices and how practices constitute particular realities, and how power is relevant in all of that. These are questions that people take up differently but they have a place in everyone’s approach around the general idea of how do we—so much of the language of this has become more and more problematic-but how do we provide ‘care’ for people who are older and frail and needing *something*. . . . But that’s why we are thinking in terms of frailty . . . there’re reasons

why these people are there, are involved. Is it a matter of the distinction being that these are practices that aren't oriented to fixing people, that there's an ongoing-ness to the practices that are initiated because of frailty of some sort?

Mary Ellen Purkis: What I kind of like about it actually, the concept of frailty, is that it's—it isn't something that can be fixed, it's only something that can be supported. You can support people who are frail to be a little less frail; you can't fix it . . . which is maybe what a lot of home care practice is trying but failing to do.

Hanne Marlene Dahl: There is a sense that the configurations of the elderly and the home helper, they don't seem to fit, and the reason that they don't fit is that the [policy] discourse, when it articulates the elderly person, it very much continues this 'will to the pleasant', which is sort of a pun on Foucault's will to power . . . all the positive, good things in the elderly get articulated whereas all the fragility and all the sadness disappears. So there is this will to the pleasant where strength and empowerment and self-determination are strongly articulated and all the other things are silenced.

HOME

And this is the allure of home care: the home as a pleasant, comfortable, comforting, healing space, as though the space itself would do a good bit of the work that is required by frail elders. But home is a contested and diverse space (Yanzi and Rosenberg 2008). For some it offers the familiarity and support of well-known nooks and corners, a place surrounded by neighbors who keep a respectful 'eye' on one another; for others home represents a dangerous and isolating prison where only luck reveals an individual in desperate need of care and support. Home can be as inhospitable a space as the most unreconstituted asylums of the distant past. In and of itself, it cannot heal. But networked with people and services and an ethos of concern for others, a supportive environment can emerge (Coles 1999).

Each of the contributors to this volume has approached their research in full recognition of these contestations regarding home and each takes up the perspective of those for whom care in the home is of concern. For instance, Davina Allen (this volume) examines the ways in which hospital staff mediate opportunities for hospitalized patients to return to their homes, with or without formal supports, to rehabilitate following hospitalization or, indeed, to simply pick up their lives where they left off prior to hospitalization. Allen's paper demonstrates an interesting and potentially problematic gap in understanding the extent to which frail older adults and those living with significant chronic illness function more effectively within

their own home environment than may be evident in the institutional context. By contrast, Hanne Marlene Dahl (this volume) approaches the topic from the perspective of policy makers who have responsibilities for establishing standards for service provision and ensuring accountability for the expenditure of public funds. Dahl's chapter demonstrates the effects and impacts imposed through a discourse of quality rather than care for those charged with providing assistance to frail elders living in the community, as well as for the experience of that care provision.

These chapters offer eloquent insights into the tensions that become apparent when the oppositions of home as prison and home as space of healing are explicitly drawn. The ideas expressed here stimulate questions, and give consideration to just how much surveillance any one person is willing to subject themselves to in order to ensure that early signs of slow decline will be noticed and acted upon in an appropriate way. The chapters also allow us to give consideration to both how and where home-based care may transform a frail elder's daily experience of life from *quality* into *endurance*.

What can we learn from these descriptions and analyses? One outcome is most notable and that is that the idea of 'home' can no longer be taken at face value. For, as Joanna Latimer (this volume) sets out, we should not confuse the idea of 'home' for the house where we live. Indeed, Latimer focuses on precisely those situations whereby people make themselves at home—anywhere! And, in thinking of home *this* way, we can at least partially detach from the notion of a built space when we think of care at home: Latimer's contribution encourages us to think *as well* about the possibilities of enabling people to *be* at home—in spaces *beyond* their own empirical 'homes'.

In drawing our attention to such insights and offering us new ways to think about the possibilities and challenges confronting us all as we seek to live meaningfully as we age, the contributors to this volume advance the dialogue about home care and care for the elderly. The efforts taken during our time together to acknowledge with respect the critical literature on home care that we advance from, the way that literature has tended to focus on the disproportionate and negative impact that home care programs have on women (see Armstrong, Armstrong and Scott-Dixon 2008; Benoit and Hallgrímsdóttir 2011, Williams and Crooks 2008). In the conversation that follows, readers will hear the points of departure that the contributions in this volume take from that base.

In Conversation (2)

Mary Ellen Purkis: So I thought, "what is it about a home that would make it be a place for somebody where they would want to be cared for? What are the considerations?" Most of what

I read that comes out of healthcare and nursing on community is the happy community, the helpful community, the goodness of community . . . and it doesn't necessarily appeal to me. A lot of the people that I worry about who are frail, it doesn't seem to me like it would be a very solid thing to imagine that the community was going to look after you, and I think that that's probably *not* most people's experience these days. . . .

Joanna Latimer: I'm very interested in people, how some people can make themselves at home anywhere. I'm very interested in getting rid of the idea of home being your house. I think that's something we're positioned into very much at the moment: you own your own home; your own home is a space of identity, work and consumption, and all the rest of it; it's another cultural performance. So I'm very interested this idea that home isn't a site of ontological security, home is something people make together.

Sirpa Wrede: They're starting to look back at the situation in Finland in the late 1990s, after a recession with very heavy cuts being implemented in home care. It became a powerful experience—finding out we were looking at a loss of a knowledge base in the Nordic context, in terms of there having existed an investment in what we called *socially defined care* . . . meaning that the starting point for home care was helping the person to hold onto their lifestyle of choice for as long as possible in a home context, if that was their wish. Because for a long time, residential care was not considered to be something to be avoided with every means, but there was also the option for home care—before what you could identify as neo-liberal reforms.

Kristin Björnsdóttir: Studying the history of nursing in Iceland, I found so many instances where home care had been flourishing, so I wondered why from the middle of the 20th century, there was almost no mention of home care. As I was doing this, I was reading literature from other countries where there was this call for home care—that wasn't really happening in Iceland because the Icelandic nation is still quite young and we had a lot of nursing homes, so basically that was the way to do it in Iceland—when the time has come, we go to a nursing home. But I was reading this literature and becoming more and more critical about all this work being dumped on women: what is it going to mean for them and for the future. And now there is this reframing of the situation where all of a sudden, things that used to be the responsibility of the state—you know, coming from a Nordic culture where the