Abstract

Over the past 50 years, agendas for less institutionalised, more autonomous, equitable and less costly medical care have shifted medical care delivery. This paper, as part of a larger study, assesses cancer carers’ experiences within hospitals following these political and economic shifts using interview data from a longitudinal qualitative study of 32 carers of a spouse with cancer. Analysis shows that cancer patients experience factory-like and inconsistent care within medical systems. Observing the flaws of the system and the impact of these flaws on patients, spouse carers feel compelled to coordinate patient care. Their accounts show that carers are now relied upon to manage patients’ care. I argue that carers are the pawns in a strategy to reduce medical spending and offer the revised concept home at the hospital to explain the medical system’s current dependence on carers to provide care in their homes and at the hospital.

Keywords: sociology of health and illness, cancer, caregiving, hospital in the home, hospital at home
Background
Fifty years ago, most serious illnesses were treated on a long term, inpatient basis. Hospital care followed a ‘total’ care (Goffman 1968) and paternalistic, ‘doctor knows best’ model (Skene 1990:43; Surbone 2006). Gradually, changes in the structure and funding of the Australian medical system over the past few decades have shifted care to the home. There were four main forces behind this healthcare reform.

One impetus was the growing sentiment that hospitals are too ‘impersonal’ (Little 1995:2). The cold interactions in institutions detailed in exposés such as Goffman’s (1968) motivated a desire for more personalised and holistic patient care, especially for those patients in palliative care (Kissane & Bloch 2002; Opie 1992).

Simultaneously, an increasing dislike for paternalism in medical interactions provided a second force behind the transition (Duckett 2004). An increasingly well informed public, with access to the internet, formed consumer groups, took legal action and pushed for patient autonomy (Duckett 2004; Turner 2006). Patients and families began demanding that they be more involved in patient care.

An arguably false nostalgia for a sense of community also compelled the move from hospital to home, providing a third impetus for change (Petersen 1994). Policymakers responded by relocating much of the caring from the hospital to the community. Now, ‘care in the community’ has replaced institutions and hospitals as the location where most medical services are provided (Duckett 2004:206) and community services are the ‘glue’ (Burns et al. 2004:501) or quick fix (Petersen 1994) that allow cancer patients to spend the majority of their infirmity at home.

The need to curtail government spending, however, provided the strongest and fourth incentive for healthcare reform. Equity in access to healthcare became an ethical and political imperative (Davis and George 1993; Duckett 2004). With universal insurance, however, came a more urgent need to contain medical spending (Davis and George 1993; Duckett 2004). Limiting medical spending, however, is problematic with calls for more spending coming from both the supply and demand side: a higher than anticipated number of Australians relying on Medicare, an aging population driving up current and predicted rates of morbidity and service use and increasing specialisation and technology pushing up the cost
of medical services (Anderson and Hussey 2000; Duckett 2004). Thus, the demand for costly services was and is increasing while government expenditure remains limited.

To balance the moral necessity (universal access to healthcare) with a financial reality (restricted public spending), economic principles were brought in to lower costs. Indubitably, treating patients outside of pricey hospital wards and having families provide the bulk of the care in their homes is more ‘cost-effective’ (National Cancer Control Initiative 2003:47). But, what impact is this having on family carers? To answer this question, I examined spouse carers of cancer patients’ experiences within the Australian medical system, using interview data.

**Methods**

With the support of local cancer services, using a quasi-grounded theory approach, 32 interviewees, 18 husbands and 14 wives caring for a spouse with cancer, were recruited through questionnaires and purposive convenience sampling as part of a larger study on carers of cancer patients. The selection of spouse carers was seen as necessary given the differing experiences of spouses, parents and children as caregivers (Thompson 2005).

Participants were between 30 and 89 years old: most between 50 and 69. Nineteen interviewees were actively providing care to their spouse. The remaining 13 had been cancer carers in the past and their spouses’ cancers were now either in remission or the cause of their spouses’ death. Several couples had taken turns as both patient and carer. The types of cancer affecting interviewees’ spouses included breast, prostate, neurological, haematological, bladder, glandular, oral and bowel cancers. All but two were interviewed twice, roughly six months apart to allow for longitudinal comparison. An *Nvivo* facilitated thematic coding approach was taken to analysis.

This analysis showed that cancer patients experience factory-like and inconsistent care within medical systems. Observing the flaws of the system and the impact of these flaws on patients, spouse carers felt compelled to coordinate patient care. Their descriptions show that carers are now relied upon to manage patients’ care. In the following sections, their accounts (all names are pseudonyms) are provided.

**Carers’ hospital experiences: inconsistent and fragmented**

Interviewees described the current state of care as one where medical staff have good intentions, but mistakes often occur, care is fragmented and carers are relied on to oversee
patient care. Respondents generally described medical staff as diligent, friendly, well meaning and hard working. They phoned on weekends, gave out their mobile telephone numbers, made house calls, stayed behind after hours to ensure that they ‘acted immediately’ to get the ‘process started’ and postponed lunch to treat patients (Charlie). On the whole, carers perceived doctors, GPs, oncologists, surgeons and radio-oncologists to be overworked from doing everything they could for patients, with intermittent success.

However, mistakes were common. Medical staff forgot to give Sally’s husband painkillers during a procedure to implant a stent. They forgot to get Matthew’s wife anti-nausea medication after chemotherapy. Anne’s husband was given the wrong anti-nausea medication. Many carers reported miscommunications, especially in emergency, such as messages from oncologists and hospice staff being misplaced, hindering a carer’s ability to get the patient access to medical attention. This corresponds to national assessments of hospital mistakes. Duckett’s (2004) survey of the literature reports that one-sixth to one-tenth of all hospital admissions in Australia result in iatrogenic injury ranging from undesirable medication side-effects to operations on the wrong patient or body part.

In addition to errors in physical treatment, most carers found that communication was inconsistent and found the hospital system to be segmented. Particularly in the public system, carers complained that service was compartmentalised, biomedical, slow, and matter-of-fact. They used words like ‘sausage factory’ (Charlie) and ‘factory of drawers’ (Bernard) to describe the organisation of care in certain departments, or ‘block of meat’ (Kyle) and ‘number’ (Bernard) to describe how patients were treated.

Communication from and between hospital staff and GPs was also described as hazy and ineffective. Poor communication and a lack of continuity of care are common complaints in most medical systems (Duckett 2004; Kiss and Sollner 2006). In Tyler’s assessment, when ‘you are dealing with a complex system…communication is just going to break down.’ This is especially the case in cancer care with patients being referred from a GP to a surgeon, to an oncologist, radiologist and other relevant specialists (Parliament of Australia Senate 2005). Judy’s account illustrates this point. She said carers and patients are left to find their way through the system and coordinate with multiple players and wards. In the past her family doctor coordinated care, but few people today, she and her husband included, have a family doctor. Without one, she was left ‘paddling in the dark.’ Cindy, a patient and a carer, said she
was certain that her doctors talked about her case at the hospital because her type of cancer was more interesting. She said, ‘If you get a few things that are rare, they [doctors] get all excited.’ Other carers were either uncertain that the doctors were talking to each other, or certain that they were not, because the carer was relied on to communicate the information. This practice of working solely within the confines of one’s position has been described as ‘fragmentation’ (Allen et al. 2004:1010), where patients are ‘passed from specialist to specialist with no clear pathway of care,’ resulting in patients, and as this research shows carers, ‘feeling abandoned’ and ‘lost’ (Parliament of Australia Senate 2005:30,8).

Relying on Carers
Carers eventually concluded that they could not leave the care of their spouse up to the inconsistent medical system; they must become the care coordinator. Fiona, for example, said to me and her husband,

   You were having transfusions and I could see the blood running out and bleeps going off and nothing happening so you run off to find someone and say, ‘Oi! I think you need to change the bag.’...You think ‘oh god, I really need to be here 24 hours a day to make sure these things are happening.’

Carers described their roles as connecting the ‘bits’ of service provided by the different medical modalities and ‘put[ting] the pieces of the puzzle together’ for their spouse (Matthew).

Tyler portrayed this medical system practice in a positive light. He was pleased that the hospital had changed over the past 40 years. When his wife was giving birth to their children in the 1960s he was banished to the waiting room to experience his fear and anxiety on his own. His experience with his wife in the hospital this time was less authoritative and more inclusive. The family, he explained, is now allowed and even encouraged to visit the patient at all hours and be part of the treatment process. His comments allude to the pendulum swing in how most hospitals operate today: swinging from commanding and total care institutions in the 1960s to a re-structured system today that more than allows family to participate. As these carer accounts show, the medical system now relies on family to provide care for patients.
Carers noticed this dependence and the necessity of their role. They described their role as navigating their spouse through the hospital system. They saw themselves as a combination of spouse and patient manager, a necessary player in patient care that provides more personalised care. Tyler, for example, said it was his job to ‘tickle’ the system and tie up all the loose scheduling ends within the hospital system. He would often have to make arrangements with the renal ward and oncology ward to change conflicting chemotherapy and dialysis appointments. The hospital system, he said, ‘still needed somebody to wander around…[and] tie it all together…that last five percent.’

But most other carers saw themselves as more than just ‘tickling.’ Instead, they interpreted their role as involving ‘case’ or ‘project management’ (Linda, Tyler, Andrew), administration (Kyle), appointment coordination (seven carers saw themselves as coordinators) and being a ‘patient advocate’ (Sharon, Phyllis). Only a few carers with a long term and trusted GP relied on their physician to oversee their spouse’s care. Most carers saw themselves as essential to ensuring their spouse received accurate care: the right diagnosis and the right medication, at home and in the hospital. This involved record keeping and actively persuading medical staff to change their treatment for the patient’s benefit.

Keeping records of doctor-patient interactions was a primary task undertaken by almost all carers. Concerns about deference, communication and the subject matter often dominate patients’ attention in medical interactions making recollection difficult (Davis and George 1993:269; McNamara 2001:87). As Phyllis noted, ‘when you are really stressed you can’t take it [information] in.’ Thus, carers took notes, collected scans, operation reports and prescriptions and then presented this overview to relevant medical professionals when needed. However, carers who wanted to be more than passive information recipients often encountered difficulties. When diagnosis and treatment information were not communicated to carers, many carers had to wait hours for a specific doctor to return to get their questions answered or rely on the patient for information, despite the known limits of information absorption in patients experiencing post-diagnosis shock or treatment (Docherty 2004). Phyllis, for instance, waited nine hours to speak to the Intensive Care Unit (ICU) doctor about her husband’s prognosis. Other than being a record keeper, any further involvement depended on the patient’s wellbeing and the doctor’s perceptions of the carer as either part of the care unit or more often, outside of the doctor-patient relationship.
As the patient’s morbidity increased, in the short term because of treatment or in the long term because of progressing disease, many carers became active patient advocates. Carers advocated to ensure their spouse got the right diagnosis and treatment. They learned that they could not rely on the hospital system to thoroughly oversee his or her wellbeing and they learned that they did not get results by patiently waiting for someone else to notice the problem. Carers had to intervene, ‘push politely’ (Marian), ‘become really assertive’ (Phyllis) or even be ‘an absolute bitch’ (Linda) to organise the care their spouse needed. Their duty to their spouse overrode etiquette.

Requests of medical staff ranged from mundane, such as asking nurses for bedpans and meals, to challenging, such as arranging for a second opinion or even urging medical staff to consider different assessment or treatment options. These ‘expert carers’ (Allen 2000) researched their spouse’s disease, monitored their health, persuaded medical staff to perform scans, arranged clinical trial participation or pressured staff to re-evaluate their initial diagnosis based on the carer’s observations and research. Linda’s story provides the most extreme example of a carer feeling compelled to advocate. Linda urged medical staff to reconsider their first diagnosis for four months. They initially thought it was an abscess in his abdomen as a result of gangrenous appendicitis. The medical staff kept draining it without results and prescribing antibiotics. They thought he was improving after each course of antibiotics, but Linda had a contradicting long term perspective. She found that the antibiotics made a slight improvement in how he was feeling, but never eventuated in a full recovery; he was continuing to decline in the long term. If she had not consistently campaigned medical staff for a re-evaluation, they would have left the abdominal bulge in situ and he would have died soon after.

Doctors and medical staff, however, did not always respond favourably to carers’ requests. Despite the ‘tension’ (Allen 2000:158) that surfaced between carers and medical staff from advocacy work, carers perceived themselves as essential players in a complex and inconsistent hospital system. They felt compelled to ensure their spouses’ care was not the result of luck, but of measured decisions and coordination.

**Home at the Hospital**

Dependence on carers to fill in the many ‘cracks’ within cancer care reflects the changes that have occurred politically and financially within Australia’s medical systems. The drive for
more personal care, for patient autonomy, for community participation, for equal access to medical services and the rising cost of medical services resulted in care being outsourced to, first ‘care in the community’ and then ‘care by the community’ (my emphasis, Allen 2000:150). That is, these changes in the structure and funding of the Australian medical system have resulted in a 180 degree shift. Family were excluded from patients’ bedsides during the mid-twentieth century. Now, family carers are relied on to not only provide care at home, but care in the hospital as well.

Patients are increasingly treated during the day, rather than at night, and most acute care is provided in the home (Duckett 2004). In place of long inpatient care, community-based medical professionals visit patients in their home. This is done to either avoid admission to a hospital entirely or to provide safe ‘early discharge’ (Duckett 2004:138). This trend of shorter hospital stays, with the patient spending more of their time at home under the care of a nurse who visits the patient at home is referred to as ‘hospital in the home’ (Duckett 2004:138). Hospital in the home or ‘care in the community’ was gradually replaced by ‘hospital at home’ and ‘care by the community’ (Allen 2000:150; White 2006:105). These latter terms acknowledge those who have now become the biggest providers of patient care: not community medical staff, but the family.

The findings presented here show that practices have shifted even further: from institutional, to hospital in the home, to hospital at home, to home at the hospital. Informal caregivers now supply between 55 and 80 percent of patient care (Jansma et al. 2005; Lewis 2006). Thus, home at the hospital now reflects the experiences of many carers of a spouse with cancer. In addition to providing care at home, carers are now relied on to manage patient care within the hospital. With bulk billing group practices replacing ‘the trusted family doctor,’ with medicine becoming increasingly specialised and with the relocation of care from the hospital to ‘many different centres’ (Davis and George 1993:163; Skene 1990:1-2), carers are increasingly counted on to coordinate care for their sick relative within the hospital wards and other medical service centres.

This outcome may reflect the original goals of community participation: allowing the community to ‘take control’ and ‘make decisions about their health’ instead of relying on a paternalistic medical interaction (Petersen 1994:110). It also, however, reflects the interests of ‘state power’ (Petersen 1994:122), saving the government approximately $30.5 billion
each year (Hughes 2007). This goal has been sustained because of the cost and meaning attached to caring. Few families can afford to pay for professional care and caring for family members at home is considered emotionally rewarding, moral and even obligatory for spouses because of ‘in sickness and in health’ marital vows (Allen et al. 2004:1020; Weitzner et al. 2000). Thus, family carers are the pawns in a strategy to reduce medical spending. Although they gain more contact with their sick loved one, they also gain more responsibility and stress.

Summary
This paper illustrates a noteworthy finding; family carers are now relied upon to coordinate care within and between medical systems, to keep records and perform patient advocacy work. This paper offers the concept home at the hospital to facilitate further discussion of the impacts that neo-liberal, universal access and patient autonomy agendas are having on medical care.

The findings presented here also suggest the need for further research to ease the confusion and burden being placed on carers. Allen et al. (2004) have made substantial strides in establishing how, using game theory, family carers and medical care teams negotiate and divide care work. Future research should focus on understanding the processes in which cancer patient care work is coordinated between medical professionals and family (what Strauss (1985) calls articulation work). Further, given the well established mental health vulnerabilities of this population (Chambers 2001; Hodges 2005, Northouse 2000; Weitzner et al. 2000), this should be applied research.

1 In Becker et al.’s ([1961]1977) Boys in White interns were found to spend more time learning from patients with rare diseases as these uncommon experiences were found to impress their superiors.

References


