

Patient safety has evolved and developed in the context of hospital care. The understanding we have of the epidemiology of error and harm, the causes and contributory factors and the potential solutions are almost entirely hospital based. Safety in home care is likely to require different concepts, approaches and solutions. Safety in this context has however been barely addressed and yet care provided in the home will soon become the most important context for healthcare delivery.

The term ‘home care’ can encompass a variety of residential settings in which people are cared for by family, nurses and other professionals. In this chapter we use the term in a more restricted way to refer to the care of people in their own home, with varying degrees of informal and professional support. We focus on people with illnesses, usually chronic conditions, who are either living independently or being supported in their own homes by family or professional carers. Much healthcare is already delivered in the patient’s home and this form of provision is growing rapidly. The benefits of home based care have been widely discussed, but the risks have not been fully articulated. In this chapter we first briefly summarise the background to the expansion of home care and then consider the nature and challenges for patient safety and the strategies that might help us manage risk in the home.

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## **An Ageing Population and the Expansion of Home Care**

More than 20 % of citizens in developed countries will be over 65 in 2020. These people, while enjoying better quality of life than previous generations, will suffer from a variety of long term conditions. As we discussed earlier, patients with cancer, heart disease, dementia, renal and respiratory disorders may now live for decades with their disease. The most common causes of disability however are due to sight and hearing disorders which affect very large numbers of people and are particularly pertinent to safety in the home. As well as an absolute increase in the numbers of older people, there will also be a considerable relative increase. The so-called ‘support ratio’ – the ratio of people of working age to those over 65 – will

decline substantially. Due to urbanization, migration and other factors frail older people will be more likely to live alone (United Nations Population Fund 2012).

Avoiding unnecessary hospitalization is a high priority for people living with chronic conditions. Once admitted to hospital, older adults are at an increased risk of poor outcomes such as readmission, increased length of stay, functional decline, iatrogenic complications and nursing home placement (Lang et al. 2008a; Hartgerink et al. 2014). The primary goals for care in the home are to avoid rehospitalisation and maintain a good quality of life.

A substantial growth of home care services appears to be inevitable. There has been a 50 % average increase of ‘hospital at home’ services in the past 10 years in Western countries and the rate is accelerating steeply. For instance in the United States 1.7 million people are currently employed as home care workers, with 7.2 million patients benefitting from these services. However the number of people receiving home care services is projected to rise to ten million by 2018 and to 34 million by 2030 (Gershon et al. 2012). This growing demand for the provision of nursing and rehabilitative care in the home as an alternative to hospital care contrasts with a scant literature on the safety, effectiveness and acceptability of hospital-at-home programmes, and evidence about their relative costs (Harris et al. 2005).

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## The Challenges of Delivering Healthcare in the Home

The familiar hospital model of healthcare delivery cannot easily be adapted to care delivered in the person’s home. Patients are much more autonomous and coordination between professionals is much more difficult. Patients and carers play a much more active role and take on many responsibilities that are, in other settings, the prerogative of professionals. They may be responsible for care planning, for sharing relevant information with providers and for execution of care plans, including carrying out home monitoring and therapeutic regimens (Lorincz et al. 2011).

Patients and carers also have an important role in diagnosis and assessment, in that they must assess the seriousness of any change in condition and decide when, and how quickly, to escalate the response by bringing in other services. Their decisions may not concur with those made by the professionals involved (Barber 2002). Home care in all its forms needs to be negotiated to a much greater extent than in other settings in which professional values and organisation hold sway. In this context, patient preferences and values will often have a higher priority than medical guidelines and recommendations. Ultimately, it is the patients, their families and caregivers who decide what they will or will not do or accept (Stajduhar 2002).

To be at home is comforting for patients because of the familiarity of the environment and the trust in carers. The home looks very different to professionals who see multiple problems such as lack of knowledge, fall-inducing obstacles, unpackaged medications, misuse of proper disposal containers for syringe and needle and so on.

Professionals cannot determine the standard of safety independently of the recipients' perspectives, because such standards will have an impact not only on the patient but also on the lives of everyone involved.

While there is general agreement on the challenges of delivering care at home, there is huge variation in how different countries are responding to the challenge. In a recent seminar at the Institute of Healthcare Improvement (IHI 2014), United States representatives described a strategy of investing in the rapid development of information technology (such as tele-health and biosensors) as the ultimate solution for greater safety and efficiency of community and home care. In striking contrast, many other countries represented (particularly Japan, the Netherlands and Finland) were primarily aiming to improve solidarity among families and citizens, reduce disparities and refocus the role of doctors and nurses while maintaining affordable home care. Japan has trained "dementia supporters" who are expected to have the necessary knowledge and skills to support people with dementia and to create and promote a supportive culture for dementia. These different approaches make very different assumptions about how care is best managed but all will face major challenges in managing risk and maintaining safety.

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## The Hazards of Home Care: New Risks, New Challenges

In the last 20 years a series of studies have revealed the hazards of care in hospital. In consequence we tend to assume that patients will be safer at home; this is no doubt true for people who are relatively well, but may not be true for the frail and vulnerable. Care at home could, in some circumstances, generate even more adverse events than hospitals. The advancing age of the average patients at home and increasing numbers of comorbidities and medications are all associated with increased risk of experiencing a medication error or an adverse event (Lorincz et al. 2011). We cannot foresee all the potential hazards but studies are beginning to illuminate some of the dangers to patients and to carers.

### Accidental Injury in the Home

Home is a more dangerous environment than most of us imagine. The leading causes of unintentional home injury deaths are falls, poisoning, fire and burns, airway obstruction, and drowning. Elderly residents are disproportionately affected, accounting for more than 2.3 million home injuries and 7000 unintentional home injury deaths annually in the United States (Gershon et al. 2012). People who are both old and ill are likely to be still more vulnerable to accidental injury. Risk factors include decline in physical or mental function, unsafe behaviours (such as smoking), living alone and health care management factors such as polypharmacy and lack of medication review (Doran et al. 2009).

## Adverse Events in Home Care

An early study of home care in Canada found that 5.5 % of 279 home care clients suffered adverse events; injurious falls accounted for nearly half, followed by medication-related events, pressure ulcers and psychological harm (Johnson 2005). Two recent studies, one conducted in the USA (Madigan 2007) and the other in Canada (Sears et al. 2013), found that 13 % of home care patients experienced an adverse event. Larger estimates based on expert chart review of 1200 patients discharged in 2009–2010 in Canada showed a rate of 4.4 % adverse events (Blais et al. 2013). The most frequent were injuries from falls, wound infections, behavioural or mental health problems and adverse outcomes from medication errors. The number of comorbid conditions and the level of dependency greatly increased the risk of experiencing an adverse event. Patients can also be victims of abuse from family members, which might not always be readily apparent to care providers (MacDonald et al. 2011).

## Adverse Drug Events

Adverse drug events have been the most studied safety issue in the home. Some studies have found that as many as 5 % of patients who were receiving nursing support at home had suffered from an adverse drug event of some kind during the previous week (Ellenbecker et al. 2004) and 25 % in the past 3 months (Sorensen et al. 2005). These problems are often due to poor communication between hospital staff, patients and their doctors in primary care (Ellenbecker et al. 2004). Few studies directly assess medication error caused by patients and family members, though models of human error should be equally applicable to patients and informal caregivers as to professionals (Barber 2002). In an Australian study, 35 % of readmissions were associated with incorrect drug administration at home. Those who had large stocks of medication at home were more exposed to adverse events (Sorensen et al. 2005). The majority of patients receiving home care services are taking more than five prescription drugs and over a third of patients are taking medications in ways that deviated from the prescribed medication regimen (Ellenbecker et al. 2004).

## Risk to Family and Other Care Givers

Unpaid carers are particularly vulnerable to stress, long term burn out and ill health. Although health care aides play a role in giving assistance, the range of tasks falling to carers is considerable: assistance with eating, moving, washing, cleaning, connecting systems, improvising when systems fail, making decision on drug doses adjustments and responding to symptoms, often without any external advice or guidance.

Caring for a person with dementia is a full time occupation with no restriction on hours or oversight from the occupational health and safety regulations which protect

professionals. Care at home is viewed positively as reducing the burden on the healthcare system; it might be more accurate to say that the burden is being transferred to the family and the patient themselves. The safety of professional care givers is also of concern, in that they are often sole workers who need to venture into dangerous areas to care for people who may themselves be dangerous. Increasing use of home care is bound to increase these risks, although these can be mitigated with proper support and appropriate technologies.

## **Problems of Transition and Coordination**

The period following discharge from hospital is a particularly vulnerable time for patients. About half of adults experience a medical error after hospital discharge, and 19–23 % suffer an adverse event, most commonly an adverse drug event (Greenwald et al. 2007; Kripalani et al. 2007). Hospital discharge is poorly standardized and is characterized by discontinuity and fragmentation of care. At the time of first follow up with their primary doctors after hospitalization, up to 75 % of patients find that discharge summaries have not yet arrived which restricts their doctor's ability to provide adequate follow-up care (Schoen et al. 2012).

The above hazards illustrate some of the more obvious potential risks to patients and carers in the home environment. However the literature is not extensive and still primarily guided by a hospital based vision of adverse events. We are far from having a full picture of the combined benefits and risks of home care in relation to care provided in other settings.

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## **Influences on Safety of Healthcare Delivered in the Home**

Patient safety at home cannot be conceptualized or managed in the same way as patient safety in hospital because of the very different environment, roles, responsibilities, standards, supervision and regulatory context of home care. People are cared for in their homes and within the context of their family and the daily lives of all concerned. The quality and safety of care is influenced by the nature of formal service provision and the characteristics of the client receiving care, the physical environment and the availability of family and other carers (Hirdes et al. 2004; Lang et al. 2008b). We outline some of the main factors that will need to be assessed and understood when designing safe home care services.

## **Socio-economic Conditions Take on a Much Greater Importance**

In an institutional setting, patients receive a certain standard of care regardless of their socioeconomic or cognitive status. In contrast, resources and environment of the home will vary hugely by socio-economic status. Wealthier people will be able to have a much higher standard of home care; they will have space for separate

'hospital' accommodation, paid support workers, leisure, better nutrition, less disruption of family life, and a higher probability that relatives can 'work' as carers. If a reasonable standard is to be achieved in poorer homes specific resources would have to be allocated to poorer families and to supporting the medical professionals in charge of those patients at higher social risk.

The elderly and disabled can be supported in their own environment 24 h a day by numerous 'smart' devices (Anker et al. 2011). Advances in telecommunication technologies have created new opportunities to provide tele medical care as an adjunct to medical management of patients. Feeling safer comes with a cost however, and that cost is often paid by the family. Contemporary homes are not typically designed or envisioned as places where complex or long-term health care is provided. The plethora of intrusive equipment, combined with the continual presence of carers, can make the person feel that their home is no longer a home.

## The Home Environment as Risk Factor

The role of design in either degrading or promoting patient safety is increasingly understood. New hospitals may now be built with safety in mind, using good design to reduce equipment problems, assist infection control and reduce errors of all kinds (Reiling 2006). Once we move into the home, this hard won gain in understanding is largely lost. Stressful and potentially hazardous conditions, such as poor lighting, excessive clutter, presence of vermin, and aggressive family members, inadequate or unavailable sharps containers, and lack of readily accessible personal protective equipment, can directly or indirectly greatly increase the risk of adverse events in this population (Gershon et al. 2009, 2012).

In some homes performing clean or sterile procedures may be almost impossible. There is also the possibility that home care staff may transmit infections between homes, particularly when patients have been discharged after contacting MRSA or C-difficile. Hand washing provides some protection but cleaning equipment in the home environment is challenging (MacDonald et al. 2011).

The Household safety survey checklist (Table 8.1) includes the checking of fire and electrical risks, ergonomic (falls hazards), biological (unsanitary conditions), chemical, and other problems such as noise, temperature, poor security and violence. Additional items address various patient characteristics that influence safety. These include age, sex, health status, ability to walk without help, number of people in the household, daily medication, methods patients use to keep track of medications, presence of any medication in the home that patients no longer take, hearing aid use and the use of durable medical equipment and safety devices.

## Increasing Responsibilities of Carers

Responsibility for safety at home largely falls on the shoulders of the patient, family members and informal carers. Caregivers are a particularly vulnerable group with

**Table 8.1** Safety checklist for household hazardous conditions

Hazard categories	
Fall hazards	No non-slip mat in shower
	No grabs bars in shower or bath
	No nonslip rug on bathroom floor
	Loose or worn rugs or carpets
	Poor lighting
	Uneven or slippery floors
	Excessive clutter
	Awkwardly placed furniture
Fire and electrical hazards	No fire extinguisher
	No carbon monoxide alarm
	No smoke alarm
	Electrical cords damaged or overloaded
	Unsafe smoking materials
	Dangerous space heater
	Stove/cooker controls hard to reach
	Flammables near cooker top
Biological, hygiene and chemical hazards	Signs of cockroaches
	Signs of rats or mice in the home
	Excessive dust or animal hair
	Signs of lice, fleas or bed bugs
	Mould or fungus
	Rotten food or milk in the home
	Rubbish building up in the home
	Food not stored in a sanitary manner
	Cleaning products and other potential poisons are not in their original containers (original labels not in place)
Other miscellaneous hazards	No emergency contact list available (for family, doctor and others)
	Excessively load noise in the home (from either inside or outside)
	Doors lacking robust locks
	Threat of violence from aggressive dogs or other pets
	Threat of violence from neighbours
	Presence of weapons

Adapted from Gershon et al. (2012)

an increased risk for burnout, fatigue and depression. Some family members or friends work 24 h a day, 7 days a week, and a number of them try to continue their work outside the home. Family and other unpaid caregivers often make promises out of love and a sense of responsibility to keep the client at home, without being aware that this may be beyond their capacity (Stajduhar 2002).

## The Training and Experience of Home Care Aides

Home care support workers play a significant role in maintaining safety at home. In the United States for example, with more than two million home healthcare employees and an anticipated employment growth of 48 % by 2018, the home healthcare workforce sector is the fastest growing in the U.S. healthcare system (Gershon et al. 2012). Home care aides help keep patients safe (Donelan et al. 2002) but they can also contribute to adverse events. Almost all are engaged in medication administration, but many lack knowledge of medicines. A Swedish study suggested that home care aides had a poor understanding of the hazards of the drugs they administer. Only 55 % knew the correct indications for common drugs and only 25 % knew the contraindications and symptoms of adverse drug reactions (Axelson and Elmstahl 2004).

Patients, family and even paid carers may all struggle to follow basic procedures which can be much more easily overseen and controlled in a hospital environment. We cannot rely on clear procedures and a strict regulatory environment for healthcare in the home. Both patients and health care aides are apt to rely on their capacity to muddle through and recover from errors. It is therefore important to acknowledge that recovery strategies (Johnson 2005) may be more important than prevention in the context of home care.

## Fragmented Approach of Healthcare Professionals

Coordination and communication among providers and across organisations and sectors is a complex issue, especially vulnerable at the interfaces along the continuum of care (Romagnoli et al. 2013). As many as ten different professionals may be involved in the care of a patient in their home and each may be based in a different organisation and a different location. Coordination of care can be extremely problematic and there is considerable scope for the patient to receive conflicting or ambiguous recommendations which raise the risk of non-adherence and other safety issues.

In a recent UK survey, most patients expressed a preference for seeing a particular doctor, rising from 52 % among those aged 18–24 to over 80 % among those over 75. However, more than a quarter of patients reported being unable to see their preferred general practitioner consistently and recent evidence suggests that interpersonal continuity has declined in both inpatient and ambulatory care (Campbell et al. 2010; Sharma et al. 2009).

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## Safety Strategies and Interventions in the Home

Safety interventions in home care are challenging for professionals since they question usual assumptions and approaches. Priority is given to avoiding hospitalisation while increasing autonomy, and mental and social wellbeing. In this context, where



there is often a trade-off between autonomy and safety, the best and safest care is a ‘mastered compromise’ in which a team of the patient, health and social care professionals and relatives each brings their own perspective and together arrive at a negotiated way forward. We believe however that, in addition to the thoughtful negotiation with patients and families, that it will also be valuable to consider broader strategic approaches to safety.

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## Optimization Strategies in Home Care: Best Practice and System Improvement

Optimization strategies are challenging to implement in the home especially with frail older people and people with mental health problems. The opportunities to directly implement evidence based medicine or to improve the delivery of care within the home are limited. Direct improvement of care can be difficult, time consuming and to reach only a proportion of the target group as the example in Box 8.1 shows.

### **Box 8.1. Difficult Challenge for Optimisation Strategies: Lessons from a Centralised Nurse-led Cholesterol-Lowering Programme**

Lowering low-density lipoprotein (LDL) cholesterol in patients with diabetes mellitus (DM) and cardiovascular disease is critical to lowering morbidity and mortality. A team-based quality improvement programme attempted to improve compliance with evidence based medicine; registered nurses followed a detailed protocol to adjust cholesterol-lowering medications. General practitioners agreed to enrol 74 % of potential eligible patients. Thirty-six per cent of approved patients could not be reached via phone and 5.3 % declined enrolment. Of patients enrolled, 50 % did not complete the programme. Of those enrolled, median LDL decreased by 21 mg/dL and 52 % (33/64) achieved the LDL target.

The resources required to identify, enrol and continually engage eligible patients raise many concerns regarding efficiency and highlight the challenges of implementing clinical guidelines in the home and community.

Adapted from Kadehjian et al. (2014)

There are however important examples of successful initiatives which fall into the optimisation approach. Studies have examined the effectiveness of particular approaches to treatment at home, covering areas such as skin care and integrity, behaviour management, pain management and incontinence. The results of such research in nursing homes often show that “what works” involves simple, low-technology solutions that may increase staff time with patients (Stadnyk et al. 2011). In other words, the time staff spend listening to patients and carers, explaining, and coordinating may be one of the best ways of improving safety in the community and home care.

## Discharge Planning and the Journey from Hospital to Home

Improving the patient journey from hospital to home and improving communication and coordination between professionals are critical in the support of patients returning home. Clear and timely hospital discharge information, including medication reconciliation, are key to this improvement. The advent of new professions such as care managers and practice facilitators in primary care is an important development in supporting patients at home with establishing personalized medical plans, coordination of professionals and the navigation of the healthcare system.

Patients at risk of poor outcomes after discharge may benefit from a comprehensive discharge planning protocol implemented by advanced practice nurses (Tibaldi et al. 2009; Shepperd et al. 2009); one in five hospitalizations is complicated by a post discharge adverse event. In one successful intervention, a nurse discharge advocate worked with patients during their hospital stay to arrange follow-up appointments, confirm medication reconciliation, and conduct patient education with an individualized instruction booklet that was sent to their primary care provider. A clinical pharmacist called patients 2–4 days after discharge to reinforce the discharge plan and review medications. Participants in the intervention group had a lower rate of subsequent hospital utilisation (Jack et al. 2009).

### Training of Patients and Carers

Recently a member of one of our families had a cancer removed and was left with a substantial wound which needed regular dressing. The person was discharged home one day after a successful operation with the patient's partner, after minimal instruction, being responsible for the dressing of the wound, managing a drain and dealing with an incipient infection. This would, of course, have been unthinkable a few hours previously when the patient was in hospital. Fortunately the patient's partner proved adept at these rather difficult tasks. The early discharge was well intentioned and in the patient's best interest but the story illustrates how quickly professional standards are lost once the patient is discharged home.

In some settings, particularly in mental health, there is a much stronger emphasis on responsibility for the patient continuing beyond discharge and including preparation for return to home and life in the community. Physical healthcare is moving into the home and community but often without this mind-set of anticipation, preparation and continuing responsibility. If patients and carers are to take on essentially professional roles, albeit only with specific tasks, then surely they need to be trained to do so? In India, families have been co-opted as part of the workforce to help care for the patient but, in recognition of this role, they are prepared and trained (Box 8.2).

#### Box 8.2. Training Families to Deliver Care

At Narayana Health families are seen as having a crucial role in the recovery of patients following surgery. They operate a 'Care Companion Programme' to harness family members' potential and position them as an integral part of

the patient's recovery. A free structured training programme, tailored for those with low literacy levels, provides family members with simple medical skills such as monitoring vital signs, encouraging medicines adherence and supporting physical rehabilitation. The programme improves the quality and hours of care, leverages an untapped workforce, reduces costs and is universally transferable. Five thousand people a month are being trained on the programme. Given the desire to place patients and families at the centre of their care in the NHS, such training seems a practical way to help achieve it.

Adapted from Health Foundation (2014)

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## Risk Control Strategies in Home Care

Risk control strategies are difficult to impose in the home environment as much of the usual healthcare regulatory framework does not apply. We may however have to give some thought to a framework of standards and other controls as more health-care is delivered in the home, particularly when patients live in isolated or poorer areas and need additional support to make home care a reasonable option.

There are almost no national standards regulating the physical environment in which home care services are provided, a stark contrast to requirements for health-care institutions. Several household safety check lists have been developed to assess the compatibility of home with home hospitalization (Gershon et al. 2012). Imposing any restrictions may be difficult to achieve because any controls would require the full consent of the patient and family. Developing safety standards in the home presents a considerable challenge as hospital oriented approaches may have limited applicability in the home. Similar conflicts and difficulties may arise even in institutional home care settings (Box 8.3).

### **Box 8.3. Safety Standards in Home and Residential Care: Autonomy, Rights and Safety**

In French hospitals there is a legal requirement that all medication should be given to patients by professionals. Patients cannot be entrusted with their own medication. Conditions for hospitalisation at home obviously differ from conditions in the hospital. In particular the autonomy of the patient and their carers is much greater. However French regulatory authorities, given the current law, have so far been reluctant to delegate taking medication to the patient. In practice patients at home are free to act as they choose regardless of the views of the regulatory authorities. Modifying this law will require an exception to be made for home hospitalisation, with the risk of increased ambiguity about the respective roles of patients and professionals.

Regulatory systems face considerable challenges in home care. For instance, French law considers that senior residents of retirement home no longer have a private home. Their bedroom in the residence is therefore considered as their home with all associated rights and privileges including adding personal furnishing, smoking, and even cooking. This was previously entirely positive as residents were entering retirement homes in their 80s while still able to live relatively independently. With an ageing population, and growing cost of retirement homes, people are more commonly entering retirement homes in their 90s and 70 % have severe cognitive impairment problems. The risk of fire when smoking, combined with limited medical access to the patient due to personal furniture, are now very high. The internal rules and regulations often forbid smoking and adding unsuitable furniture, but can be successfully challenged by patients and their relatives as a deprivation of rights. Changing these laws is not straightforward since this issue concerns a fundamental principle of freedom given by the French Constitution.

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## **Monitoring, Adaptation and Response Strategies in Home Care**

Monitoring, adaptation and response strategies are clearly to the fore as safety strategies for home care. The assumption that healthcare staff and organisations should wait for patients to present with an illness is giving way, at least for some chronic conditions, to a more proactive approach to monitoring, detection of problems and response aided by a variety of innovations in information technology.

In the hospital monitoring and detection of problems is largely the responsibility of staff. In the home however, patients and carers need to monitor, adapt and respond. This raises the question of how, as with staff, these abilities can be supported, encouraged and perhaps trained. This requires, as in other contexts, the development of a safety culture, and potentially other transferable routines such as safety briefings. For instance a colleague, who is a carer for a family member with serious mental health problems, has described how she and her husband have developed a routine of regular morning telephone calls in which they review the day, the support for the family member, any worrying symptoms, medication availability and other issues. This is, in essence, a safety briefing. Such systems could be developed in partnership with patients and carers and become an established safety strategy. As yet however, we do not know of any attempts to develop formal safety strategies for patients and carers at home, although there are many examples of individual patients developing their own ingenious and innovative approaches.

## Detecting Deterioration

Carefully designed and implemented care management and tele health programs can improve safety and reduce health care spending (Baker et al. 2012). Many smart homes and remote monitoring solutions are emerging to support patients at home (Chan et al. 2009). The critical safety issue however is how to detect deterioration. In the context of hospitals David Bates and Eyal Zimmerman have argued that ‘finding patients before they crash’ is the next major opportunity to improve patient safety (Bates and Zimlichman 2014). In hospitals the primary tools to improve detection are the electronic health record, physiological sensors, decision analytics and mobile phones, with the assumption of a rapid clinical response once deterioration is identified. All these can potentially be employed in the home but implementation is far from straightforward.

The potential for home monitoring to improve the management of chronic conditions is considerable. Four of eleven programs that were part of the US Medicare Coordinated Care Demonstration reduced hospitalizations by 8–33 % among enrollees who had a high risk of near-term hospitalization (Brown et al. 2012). Home monitoring can come in the form of telephone support and visits, the promotion of self-care and the use of a variety of external or implantable devices. Multi-component interventions variously incorporate enhanced team communication, care planning, education and support for patients and carers, direct access to hospital care and the use of information technologies (Jaarsma et al. 2013). Tele medical monitoring service can combine with this support at home and reduce the number and duration of hospital admissions for worsening pathologies (Anker et al. 2011), though may not currently be suitable for patients with cognitive, visual or other sensory impairments (van den Berg et al. 2012). Implanted devices have been shown to be effective in reducing hospitalisation due to heart failure and reduce the need for active participation of the patient (Bui and Fonarow 2012).

### Box 8.4. New Professional Roles Emerging

The care manager’s central role is delivering and coordinating services for patients, including coordinating care across clinicians, settings, and conditions, and helping patients access and navigate the system. While these care coordination activities may benefit any patient, they can be particularly useful for those with chronic conditions and many care needs. Working closely with patients and their families, care managers’ activities often include:

- Assessing (and regularly reassessing) patients’ care needs
- Developing, reinforcing, and monitoring care plans
- Providing education and encouraging self-management
- Communicating information across clinicians and settings
- Connecting patients to community resources and social services

Adapted from Taylor et al. (2013)

It is becoming clear that successful home care requires not only monitoring but the development of a system of care which includes the selection of appropriate physiological indices, the timely interpretation of data by an experienced clinician, and a system capable of responding rapidly to provide appropriate treatment and to monitor the response to that treatment (Box 8.4). Few existing home monitoring approaches provide this full cycle of care and in addition these approaches will need to be tailored to individual patients according to disease severity, the patient's capacity for self-management, the availability of support and the home care environment (Bui and Fonarow 2012).

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## Mitigation

The benefits of providing healthcare in the home, for both minor and more serious conditions, are undoubted. As homecare becomes more complex however there will be a correspondingly greater risk of adverse events and therefore a need to anticipate and plan for a response to those events and mitigate their effects. In a hospital the rapid initiation of a remedial response to physical harm is part of routine clinical practice and we have previously discussed the need for psychological support for patients and staff. Mitigation strategies in the home will need to include consideration of both the psychological impact and preparation for an emergency response. In the event of a crisis the patient will need access to the right person at the right time; a capacity for rapid rehospitalisation whenever needed will be critical, especially at nights and week-ends.

## The Responsibilities of Carers

The recognition that staff can be seriously affected by the role they have played in an error or harmful event has been a very important step forward, although programmes for supporting staff are still rare. In the home patients and carers are increasingly taking on professional roles and therefore they too may make serious and consequential errors. If a family member makes an error they have all the burden of responsibility that a professional bears combined with the terrible experience of harming someone close to them. Interviews with carers suggest that the responsibility for giving powerful medications can become burdensome both because of the time commitment and anxiety about making mistakes; many carers do not receive clear guidance about medication, leading to omissions, incorrect doses, anxiety and confusion which are often not recognised by health professionals (While et al. 2013). Relatives of people near the end of their lives face the additional worry about hastening death through improper use of medication (Payne et al. 2014). The blurring of boundaries between family carers and professionals is difficult for all concerned particularly towards the end of a person's life. As well as providing support and training to carers, we will also have to consider how to provide support in the event of a serious error, an issue which has currently not been addressed at all.

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## Mitigation Strategies in Home Haemodialysis

Home haemodialysis is hugely beneficial for patients in that dialysis at home preserves independence and autonomy and reduces dependence on the hospital. Patients and carers can become apprehensive about performing such a complex set of tasks and fearful about the potential for dialysis related emergencies (Pauly et al. 2015). Home dialysis is generally a very safe procedure but a number of deaths due to error have been recorded, such as a man who died from exsanguination after he connected a saline bag to a blood circuit (Allcock et al. 2012). In the early stages of home dialysis patients report frequent mistakes while they learn the procedures and develop their own personal safety strategies, such as ensuring that there are no interruptions and ensuring that help is on hand in the event of problems (Rajkomar et al. 2014).

Established haemodialysis units provide training and prepare patients and carers very carefully for home dialysis procedures. Instilling a culture of safety without unduly alarming the patient, ongoing vigilance from both patients and professionals and ongoing support are critical. In addition Pauly and colleagues (2015) suggest that it is necessary to develop safety strategies to mitigate the risk of adverse events, which include the anticipation and preparation for any adverse events that do occur. They set out a series of measures which includes the provision of an explanatory letter for a patient to take to an emergency department, ensuring the patient is fully briefed in emergency procedures, and a full set of procedures for staff to initiate to respond and learn from any events that do occur. The most important lesson from their account is the preparation that they provide for patients and carers includes an explicit and comprehensive set of safety strategies as part of the basic programme.

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## Reflections on Home Care Safety

By highlighting the risks of home care safety we do not intend in any way to suggest that care in the home is not desirable or possible. On the contrary it is essential for all of us who wish to live independently for as long as possible as we age. We can also see that innovations in remote medicine, tele monitoring and smart homes may well resolve some of the safety problems we have described. However care in the home does highlight some fundamental safety issues. Most importantly there is an apparent clash between autonomy and safety, although this is only a clash if you feel that older people must adhere to an ultra-safe model of safety. In reality safety is always only one of a number of objectives and we often knowingly take risks in the pursuit of other benefits, such as travelling, sport or exploration. More than that we accept the right of people to take personal risks even though the costs of failure often fall on the wider population when they are patched up again in hospital. Safety in the home needs to be assessed in the same way, not in terms of absolute safety but alongside other benefits. This is nicely captured in the term 'the dignity of risk' used in Australia by those providing services for frail older people. The model for safety in the home then is not ultra-safe; a frail older person at home has more in common

with a deep sea trawler man than a pilot. Safety is managed by personal resilience, expertise and a high reliance on monitoring, adaptation and, most of all, recovery.

### Key Points

- Safety in home care has barely been addressed and yet care given in a person's home will soon become the most important context for healthcare delivery.
- Many home care patients experience an adverse event. The most frequent adverse events are injuries from falls, wound infections, behavioural or mental health problems and adverse outcomes from medication errors.
- Patient safety at home cannot be conceptualized or managed in the same way as patient safety in hospital because of the very different environment, roles, responsibilities, standards, supervision and regulatory context of home care.
- Stressful and potentially hazardous conditions can directly or indirectly greatly increase the risk of adverse events at home
- Safety at home falls largely on the shoulders of patients, family members and relatives. Caregivers are a particularly vulnerable group with an increased risk for burnout, fatigue and depression.
- Limited available standards and the fragmented approach of healthcare professionals make home care more prone to errors
- Safety interventions must give priority to reduce hospitalisations, increase wellbeing, increase communication among carers and with patients, and improve recovery strategies.
- There are opportunities to implement evidence based care in the home but it is considerably more difficult than in other settings. Much can be done to improve support systems, detection of problems and recovery.
- Highlighting the risks of home care does not imply that care in the home is not desirable or possible. We should not aim for absolute safety in home care but assess risks in the context of the benefits of living as independently as possible at home. Safety is managed by personal resilience, expertise and a high reliance on monitoring, adaptation and, most of all, recovery.

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