

# Healthcare Professionals' PERCEPTIONS OF RISK

## *When Care Is Given in Patients' Homes*

*Perceptions of risks in decision making for home healthcare were examined. Twenty home healthcare professionals were interviewed. Content analysis yielded one theme (management of known and unpredictable risks) and four categories. Healthcare professionals had to handle both known and unpredictable risks in daily work in patients' homes concerning communication challenges, a fragmented organization at several levels, risky medication management, and balancing respect for patient autonomy and involvement in care against risk taking. Priority must be given to creating safer care in this setting.*

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To meet the global burden of an aging and growing population, healthcare has increasingly moved from hospitals to patients' homes (McNeil et al., 2016). Early discharge from hospital to home care is common. This development is intended to increase patients' quality of life and make care more efficient, but may also generate new risks. Aging is considered to be associated with at least one chronic disease, for example, cancer, diabetes, or hypertension (World

Health Organization, 2017). It is estimated that 50 million people in Europe have multiple chronic conditions (ICARE4EU, 2013). In Sweden, 85% of people over 65 years have at least one chronic disease, and 66% have two or more (Vårdanalys, 2014) and the prevalence is similar in the United States (Buttorf et al., 2017).

Fragile older patients are also exposed to risks and adverse events (AEs) (Blais et al., 2013; Doran et al., 2013; Rafter et al., 2015; Sears et al., 2013). In

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a recent retrospective record review in home care settings in Sweden (Schildmeijer et al., 2018), AEs were identified in 37.7% of the records examined, with 71.6% of AEs considered preventable. The most common AEs found were healthcare-associated infections, falls, and pressure ulcers.

Two main organizations, county councils and municipalities deliver healthcare in Sweden. The county councils are responsible for primary care and in-hospital care, whereas the municipalities are responsible for providing long-term inpatient healthcare and home care for older adults (Anell et al., 2012).

In a report, Swedish Association of Local Authorities and Regions (SKL; 2012) it was shown that primary care, home care, and municipal home care were not taking sufficient responsibility for patients after hospitalization. Despite this, home healthcare (Blais et al., 2013; Lang, 2010; Lang et al., 2008) has not been investigated to the same extent as in-hospital care with regard to risk awareness (Baker et al., 2004; Sari et al., 2007; Soop et al., 2009). Unlike hospitals, home healthcare environments are not designed for providing healthcare (Lang, 2010). The environment in a patient's home is uncontrolled and unregulated from a safety perspective, and healthcare professionals may have limited possibilities to make changes that ensure safety (Ellenbecker et al., 2004; Ellenbecker et al., 2008; Lang & Edwards, 2006).

In decision theory, the fitness of an organization depends on how effectively it makes choices in an uncertain and varying environment (Lee, 1971). Risk is most commonly conceived as reflecting variation in possible outcomes, their likelihoods, and their subjective values (March & Shapira, 1987). People carrying out assessments need to have an understanding of the types of risks and errors and the factors that make them more or less likely (Health and Safety Executive, 2014). Individual human decision making is shown to be risk averse, that is, when a person is faced with one alternative with a certain and given outcome, and a second alternative with a less certain outcome but with the same expected value, the person will usually choose the certain outcome

rather than the less certain one (Ross, 1981). It is important to do everything “reasonably practicable” to protect people from harm. This means balancing the level of risk against the measures needed to control the risk in terms of harm, costs, or time. In all workplaces, new equipment, substances, and procedures that could engender new risks constantly appear. The greater the risk, the

more robust and reliable the measures to control the risk of harm occurring must be (Health and Safety Executive). In the Swedish healthcare system, municipalities are obliged to pay for patients who are still hospitalized more than 3 days after being assessed by the responsible physician as clinically ready for discharge and home care. As a consequence, the staff

within the municipality's organization must make decisions about early hospital discharge of severely ill patients. They also have to decide about each patient's needs and the risks an early discharge to home care would imply for the patient. In view of the large number of older adults now cared for in their homes, it is important to explore healthcare professionals' perception of risks in decision making when care is given in older patients' homes.

## Methods

We used a qualitative design with focus groups and individual interviews to capture both the depth and breadth of perceptions of decision making in home healthcare. Two focus group interviews and nine individual interviews with a total of 20 participants were held with different healthcare professionals working in patients' homes. Content analyses of all interviews were performed. Decision theory was used as a theoretical framework to get a deeper understanding of the phenomenon.

## Setting

The study was two municipalities in the southeast of Sweden. In Sweden, healthcare is mainly publicly funded. The provision of healthcare services is primarily the responsibility of the 21 county councils in Sweden. There are also 290 Swedish municipalities that have a legal obligation to take

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care of older adults in need of home care (Anell et al., 2012). Both county councils and municipalities can be responsible for care provided in patients' homes, depending on the agreements signed between the two healthcare providers. In the two municipalities where this study was performed, the county councils had the responsibility for advanced home healthcare performed by physicians and registered nurses (RNs). The physicians and RNs were part of trained palliative teams. They provide care around the clock and are granted access to hospital resources, such as specialized knowledge and advanced technology. The municipalities were responsible for public services, for example, social services and care of older adults provided by nurse assistants. Nursing care in terms of general home healthcare was provided by RNs employed by the municipalities.

### Participants

All participants were invited by email to participate in interviews concerning their perception of in-home healthcare for older adults with complex care needs. All those asked agreed to participate. The 20 participants included 6 physicians, 11 RNs, and 3 nurse assistants, and their experience of healthcare work varied between 3 and 31 years. Their experience of working with patients with complex care needs also varied greatly, from 1 to 30 years. Participants in the focus group interviews were part of hospital palliative teams ( $n = 11$ ). The participants worked as physicians with responsibility for patients with complex care needs ( $n = 2$ ), as RNs ( $n = 6$ ), or as assistant nurses ( $n = 3$ ). Individual interviews were conducted with participants located at a geographic distance from the research team. Participant characteristics are shown in Supplemental Digital Content 1 (available at <http://links.lww.com/HHN/A65>).

### Data Collection

The interviews took place between July 2015 and March 2016. The focus group interviews were performed at one of the hospitals. The individual interviews were held either at the participants' workplace or in their home, depending on their choice. The focus group interviews lasted between 80 and 90 minutes and were performed by authors KS and BW. The individual interviews lasted between 26 and 67 minutes and were conducted by author KS. All interviews started with an open-ended question: "What is your perception

of safe care?" Then, questions such as "Do you have any perception about risks in the care given to this patient population?" and "What experiences do you have of caring for older patients in home healthcare?" were asked. During the interviews, the moderator/interviewer asked probing questions, for example, "What do you mean?" or "Can you explain a little further?" Toward the end of each interview, the moderator/interviewer asked if the participants felt that anything had been missed that needed to be discussed or if they had anything more to add. All interviews were recorded and transcribed verbatim.

### Analyses of the Interviews

Interviews were analyzed using conventional content analysis as described by Hsieh and Shannon (2005). Knowledge generated from this method is based on the participants' unique perspectives. With the study aim in mind, all authors read and reread the transcripts to get a perception of the whole. Two authors (KS and BW) started to derive codes that captured essential thoughts related to the phenomenon. Next, codes with similar meanings were grouped together into clusters. The clusters were then discussed among the three authors, and by contrasting and comparing the clustered codes with the whole text, the clusters were organized into subcategories based on their content and joined into a smaller number of categories (Supplemental Digital Content 2, available at <http://links.lww.com/HHN/A66>). Finally, one theme emerged comprising at a higher abstraction level the latent content of four categories. Each interview quote was assigned a letter and a number to show which interview it was from (F1 and F2, I1–I9), thus showing that the quotes used originate from different interviews.

### Ethical Considerations

All participants gave individual informed consent to take part in the study. Ethical permission was obtained from the Regional Ethical Board of Linköping University, Sweden (no. 2014/150-31).

## Results

### Healthcare Professionals' Management of Known and Unpredictable Risks

The content of the four categories describes how the professionals constantly had to handle a deficient communication system, a fragmented organization, risky medication management, and



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decisions that included an ongoing struggle with both known and unpredictable risks of an AE occurring. This created uncertainty and an unpleasant feeling of patients being placed at risk in the transition between hospital and home care. Managing safety in home care includes calculating the value of patients being at home, and the responsibilities that patients and their families are charged with and can sometimes barely manage. The participants made decisions on a daily basis, trying to foresee and prevent risks, knowing that patients were still exposed to both known and unpredictable risks. Healthcare professionals also balanced the patients' right to autonomy and involvement in their own care with the risks that this might imply.

#### ***Different Kinds of Communication Challenges***

The problem of communication due to documentation systems was a challenge considered to be both a known and an unpredictable risk by all the responders. The participants described how professionals caring for the same patient were organized in "silos" (isolated from each other). This implied problems with access to the patient record system both within their own organization and among the different healthcare providers involved in patient care. In municipal healthcare, nurse assistants' notes on patients are written on

paper records, whereas registered healthcare professionals who are obliged to make notes use electronic records. Registered nurses from the municipalities had access to notes made by the RNs from hospital care, but this was limited to the patient's latest visit at the hospital. The in-hospital RNs did not have any access to information from the municipality record system, because the systems did not communicate. The participants were well aware of the risk for loss of important information, as illustrated by the following quote:

*"Another thing is these separate medical record systems. I see it as a giant security risk that they are even allowed to solve it this way, that all of us who are jointly caring for the patient cannot read one another's notes. It's horrible!" (F-2)*

From the responders' point of view, the electronic medical record system was poorly designed. To foresee and overcome the risk that important information was lost, professionals wrote extensive and detailed notes in patient records, which made it even harder to quickly identify essential information in the overwhelming information flow.

The participants also spoke about ethical dilemmas that appeared unpredictably as a result of lack of communication. An example was when healthcare professionals arrived at a patient's home and had not received information about the patient's death; the relatives were the ones to inform them. Communication did not work smoothly even within their own organization. The communication within the organization had similarities with "Chinese whispers," where the first person passes on a message to the next person in line by whispering in his or her ear and so on. Repeating messages over and over creates a risk that eventually the content and meaning may change completely.

*"I would talk to someone at social services, who would talk to a group manager, who would talk to the staff on the floor in social services; a summary of the medical record would be given to the nurse, who has not met the social services staff." (I-3)*

#### ***A Fragmented Organization at Several Levels***

The nurse assistants described the home care organization structure in a way that incorporated

known risks for mistakes. For instance, it was common that nurse assistants in one home care group could be moved around to cover vacancies in another district, meaning they often visited patients who they had never met before. As nurse assistants most commonly worked alone in patients' homes, there was no one to ask about patient's preferences and needs if the patient was unable to describe which care actions should be performed. This could lead to mistakes in treatment and care and missing important signals related to the patient's health status.

*"They (the patients) might be more ill than normal, but I don't notice that, since I don't know them. That isn't patient safety, to my mind." (I-6)*

Sometimes patients were discharged from the hospital on weekends, and the participants discovered a patient had new medications that they had not used before. To discharge a patient on a Friday afternoon was a known risk taken by the hospital professionals, and perceived as an unpredictable risk by the participants in this study, which they attempted to handle in order to provide safe care to patients at home.

*"They (the patients) come home on Friday afternoon and we notice only when they are going to bed that they need medication, but we don't have it at home... We might drive around looking for it, but you can't be sure we have the time and the pharmacies aren't open." (I-7)*

According to the participants, they all had to trust each other's assessments and decisions, which was also perceived as an unpredictable risk. There was uncertainty relating to the fact that the accuracy of assessments of patients' conditions could vary depending on an individual professional's knowledge and skills, experience acquired over the years, and familiarity with the patient's history, as well as his/her actual condition. The interviewees were unsure if it was possible to ensure a sufficient degree of safety, particularly for the most fragile patients.

### **Risky Medication Management**

Medication management was identified as a risk area, interpreted as both a known and an unpredictable risk. Many patients are prescribed a large

number of drugs, which increases the risk of drugs being mixed up. Several pitfalls were identified where things could easily go wrong. One risk was that both professionals and patients were unaware of changes in the patient's medication orders, and if a patient still had old medication at home, there was no guarantee that the patient was really taking the drugs prescribed.

*"It might be unclear what the patient is actually taking. The patient comes home and there are no prescriptions or medications. The risk is that the patient suffers as a result, with pain, constipation, or loneliness, before we've managed to figure it all out." (I-5)*

Participants also perceived difficulties in following up on patient medication in the home. Drug lists were often out of date, and patients got drugs from old lists in the belief that they were up to date. In addition, because drug lists were generally duplicated, the interviewees sometimes felt unsure about which list was the correct one.

*"You often end up comparing 2 medication lists with each other and having to guess which one is most recent." (I-6)*

Another risk identified was that pharmacies would supply the cheapest variant of each medicine, which meant the label, name, and appearance of medicines changed constantly. As a consequence, patients, family carers, and nurse assistants who were delegated with distributing the medication to the patient could not assess the correct medication intake.

*"The patient had 10 different kinds (of medication) in the cabinet at home, which I had given out earlier, and which they maybe shouldn't take when they go home from the hospital. It doesn't automatically turn out right just because they have a written note. They'll have 3 generic versions at home and will think: 'The green one seems right, so I'll take that one.'" (F-1)*

The participants were also concerned about the computerized pharmaceutical system, because it had flaws that were difficult to handle. The layout made it hard to read the prescriptions, and once a drug was prescribed to a patient, it remained in the system for several years. As a

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result of this system problem, it sometimes took a long time before participants discovered the dosage of a drug was wrong. There were occasions when patients did not receive prescribed drugs, and occasions when patients received too many doses of a drug. The participants stated this gave them a feeling of uncertainty and they did not trust the existing pharmaceutical system.

#### ***Balancing Respect for Patient Autonomy and Involvement in Care Against Risk Taking***

The participants mentioned they did not get sufficient information from the professionals working in the hospital. Instead, a known risk was taken in connection with the patients' hospital discharge; they were expected to be the bearers of their own information. Another unpredictable risk factor was the expectations and demands that were either implicitly or explicitly imposed on patients/families regarding involvement in their own care. The in-hospital professionals trusted the patients' knowledge, although the patients were frail with multimorbidity and cognitive impairment, and their health literacy varied considerably. All this was overwhelming for many patients. Based on the interviews, it was stated that patients could argue they were able to fend for themselves when they were discharged from hospital, when in fact they were in need of a lot of help.

*"Sometimes the patients don't even know what was done to them while they were in hospital." (F-1)*

The participants also had concerns related to who could be held responsible for some unexpected AE. A drug drip counter might sound a loud alert; to silence the noise, both family members and the patient might press different buttons on the equipment without knowing how this could affect the patient and the scheduled treatment. This created uncertainty for the participants who

were responsible for something that they could neither predict nor influence, which in turn led to an unpleasant feeling of unsafety.

#### **Discussion**

We found two types of risk factors, known and unpredictable, that healthcare professionals had to handle daily when making decisions in home care. The main areas highlighted were linked to communication challenges, a fragmented organization at several levels, risky medication management, and balancing respect for patient autonomy and involvement in care against risk taking. Some of these areas could be seen as a necessary condition for safe care but could also constitute risk factors. The participants were well aware of both known and unpredictable risks, and had to deal with them and make decisions despite a seeming lack of tools to prevent them. Khalili Damghani et al. (2009) call this "decision making under risk." This means that risk implies a degree of uncertainty and the actual outcome will not always be the expected one. The elimination of one risk may also increase the likelihood that other risks appear. In our study, the participants identified known risks resulting from patient autonomy in home healthcare, but also unpredictable risks resulting from a healthcare system with different caregivers. The participants had to consider what constitutes an acceptable threshold of risk and the appropriate way to balance that risk against the benefit to the patient of being at home. According to March and Shapira (1987), decision makers have a tendency to underestimate risks if earlier decisions have been successful. Such successes make the decision makers confident in the belief that they are also capable of handling future risks, and they underestimate the role of luck in their earlier performances.

We found the most common risk among participants was related to communication, which has also been found by others (Lang, 2010; Lang et al., 2008; McGraw et al., 2008; McNeil et al., 2016). Totman et al. (2015) described relatives' perceptions that they constantly had to fill a gap when communication among professionals failed. March and Shapira (1987) stated that the information limitations made by human beings could sometimes be modified by the organization in which they were working, but that organizations also introduced other kinds of problems. We found that different communication systems and non-

functional communication systems were seen as unpredictable risk and should not be allowed, according to the participants. Still, policy makers seem to believe the risks of electronic healthcare records are minor and easily manageable, which is not the case (Karsh et al., 2010). Quality of care and patient safety are jeopardized by flawed functionality, problems with the design of electronic healthcare records systems, or improper use (Phillips & Fleming, 2009). Based on the results in our study, we agree with Ash et al. (2004), who stated that these systems can adversely affect clinical care by generating both new tasks and more work for healthcare professionals, leading to new kinds of errors and causing workflow problems. Adequate communication, record keeping, and sharing of records are all concepts relevant to patient safety. Patient record systems should be designed to optimize clinical workflow rather than being an obstacle, and they must be improved constantly (Hansson et al., 2018).

We found that different types of care transitions could be regarded as associated with known and unpredictable types of patient risks. Patients are discharged from hospitals more quickly, providing less time for healthcare providers to prepare them for discharge (Bowles et al., 2002; Chapin et al., 2014). In addition, unprepared discharge of patients led to extra work for the participants in trying to manage the problems and risks this could cause patients. Hansson et al. (2018) also described short hospital stay, professionals' lack of time to provide information to the patient and relatives before discharge, and the lack of collaboration between professionals and care levels as potential risk factors. Despite being affected by medication, treatment, or symptoms, and while age and mental well-being can affect the perception of given information, the patient is used as a conveyer of information, which is in line with our results.

According to Goodwin and Wright (1998), probability assessment quantifies the information gap between what is known and what needs to be known for an optimal decision. In our study, lack of information between caregivers was an unpredictable risk mentioned by participants. This could jeopardize patient care, which previous research has also shown (Lang, 2010; Lang et al., 2008; McGraw et al., 2008). Bridging this difficulty requires extra thoughtfulness because of the patient comorbidity and the care organization of today. Even with the best of intentions, things might not

work out as expected. McNeil et al. (2016) described an intervention where nurses prepared both healthcare professionals and patients with an amount of information when patients were discharged. The expected result was that the care transitions would be improved. Unfortunately, they did not achieve the result they expected because the patients were highly fragile and vulnerable with complex medical conditions, and the participants considered the relevance of the information provided to be unclear. Hansson et al. (2018) requested an overarching responsibility for the patient in relation to care transitions and a technology system that could support collaboration, beyond organizational borders, to minimize risk factors.

The organization in Swedish home healthcare puts a large responsibility on the patients and their families, a responsibility that no one can demand of them. The participants have no authority over the patients or their family members. According to Linderholm and Friedrichsen (2010), healthcare professionals could sometimes take it for granted that relatives want to take on a caring role; they might even be a prerequisite for making homecare possible. The responsibility could increase, despite relatives often having limited preparedness for and knowledge of the tasks. This could pose an unpredictable risk, as the home environment may limit the healthcare professionals' ability to observe the quality of care that informal caregivers deliver (Ellenbecker et al., 2008). Further, both patients and their families are in a vulnerable and stressful position, and many of them lack knowledge about the drugs and technical equipment they are expected to handle (Romagnoli et al., 2013; Van Bruggen et al., 2016). One incorrect decision could influence the future of the patient. van Gigch (2002) stated an outcome depends upon the reactions of other people, who may be themselves doubtful. With this approach, policy makers at political or organizational levels are taking calculated risks that can jeopardize patient safety in home healthcare, a responsibility the policy makers can never disclaim.

The fact that the context differs between hospitals and home healthcare leads to specific problems with medication management (Ellenbecker et al., 2008). According to the participants we interviewed, it is common that patients already have a number of drugs in their homes. This is in line with Ellenbecker et al. (2004), who found that most older home care patients were taking more

than five prescription drugs, and in addition, they were taking their drugs in ways that deviated from the prescribed medication regimen (Dolovich et al., 2008; Mager, 2007).

### Methodological Considerations

As the settings are from the same area in Sweden, transferability of findings to other counties or regions in Sweden may be limited. The analysis was based on propositions from 20 participants and, as in all qualitative studies, it is unclear how well their participants' descriptions covered significant variations of the phenomenon under study. However, the participants were selected to have rich and various experiences of providing home care. Representative quotations from the interviews and a rich description of the context are provided to facilitate the judgment of transferability. To ensure conformability, the authors discussed the categories created and made changes until consensus was reached. The theme that emerged was also discussed and the coauthors agreed on the label of the theme and its content. To ensure dependability, a description of how data were collected and how the data were analyzed is presented.

### Conclusions

The participants perceived home healthcare for older adults with complex needs as a type of care with risks that often had to be dealt with. Both known and unpredictable risks were described, but many of them were caused by systems not being compatible with or connected to each other. Policy makers must consider the risks of delivering home healthcare. The home is usually regarded as a place of safety and security but is obviously also a place where risks are being taken. ■

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## Life in Rural America

While economic challenges in rural America have received significant national attention, a survey by NPR, the Harvard T. H. Chan School of Public Health and the Robert Wood Johnson Foundation finds that residents of rural communities consider drug addiction or abuse and economic issues as the biggest problems facing rural communities.

### Key Findings

- A majority of rural residents agree opioid addiction is a serious problem in their community (57%), with about half personally knowing someone who has struggled with opioid addiction (49%).
- Almost one-quarter of rural adults (23%) say that drug addiction or abuse is the most

urgent health problem currently facing their community, followed by cancer (12%) and access to care (11%).

- Sixty-four percent of respondents say better long-term job creation would be most helpful to their local economy; 61% believe improving quality of local schools; 55% report improving access to health care; and 51% view advanced job training or skills as recommended approaches.
- Fifty-two percent of respondents say they are active in solving problems in their local community, with younger adults reporting higher levels of participation.
- Eighty-one percent of respondents report feeling attached to their local community, and 67% say neighbors have helped them in times of need.