

pp **RESILIENS**
PROGRAMMET

Resilience From a Stakeholder Perspective: The Role of Next of Kin in Cancer Care



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Abstract

Objective

The aim of this article was to provide new knowledge on how next of kin are co-creators of resilient performance, as seen from the viewpoint of the healthcare personnel and managers. The following research question guided the study: How are next of kin involved in shaping resilience within cancer care in hospitals?

Methods

The design of the study is a case study of cancer departments in two Norwegian hospitals. Data collection included a total of 32 qualitative semistructured interviews at two organizational levels (managers and staff). The data were analyzed by ways of a directed content analysis according to Hollnagel's Resilience in Health Care framework of resilience potentials (anticipate, monitor, respond, learn).

Results

Next of kin are involved in creating and maintaining resilience in cancer care by different kind of activities and in-depth insight into the patient's condition, which strengthen all resilience potentials of responding, anticipation, monitoring, and learning. We have identified nine areas in which next of kin are co-creators in shaping resilience. Next of kin are important stakeholders, both as safety experts and as safety resources, helping healthcare professionals provide quality and safety in the patient care process under difficult conditions. Next of kin's knowledge of the patient's history, their observation of the patient over time within the hospital, at home, and across care transitions are key elements of their contribution.

Conclusions

Next of kin complement healthcare professionals in all four potentials for resilient performance. The study suggests that the Resilience in Health Care framework takes into account the role of next of kin, as a stakeholder potential, because this has not previously been sufficiently considered.

Patients with cancer experience adverse events more frequently than other hospital patients.¹ Safety in healthcare is often described as a moving target and that numerous stakeholders are involved in keeping patients safe.² Families and next of kin are described as important safety experts but are rarely included in the patient's medical team.³⁻⁷ Despite the increasing focus on patient safety in the last decade,^{8,9} studies have neglected these stakeholders.^{4,10-13}

Resilience in Healthcare

Resilience theory has entered the safety research agenda in healthcare organizations.¹⁴⁻¹⁷ Resilience theory also focuses on how healthcare is provided under various conditions and how healthcare personnel adapt their practice. In this field, stakeholders are considered important actors; however, the stakeholder perspective is underexplored in the literature.^{14,18} The latter indicate a twofold need: (1) to understand the next of kin role in healthcare organizations and (2) to explore the stakeholder phenomenon in resilience.^{19,20}

There are numerous definitions of resilience in different research traditions.²¹ In this article, we use the definition of Resilient Health Care (RHC) by Hollnagel et al¹⁵: “Resilient health care can be defined as a health care system's ability to adjust its functioning prior to, during, or following changes and disturbances, so that it can sustain required performance under both expected and unexpected conditions”[14 pp: XXV]. Hollnagel and colleagues^{14,22,23} argue that human and organizational performance depends on the following four potentials that are essential for resilient performance:

1. The potential to respond: this means to know what to do and being able to adjust and respond to expected and unexpected conditions and disturbances, by activating prepared actions or adapt mode of functioning. The ability to respond depends on the preparedness to monitor and the right resources.^{14,22,23}
2. The potential to monitor: this means knowing what to look for and being able to monitor both the organizational environment but also the operating environment, in terms of what affects or could affect the

organization's performance. Monitor is the foundation for the ability to respond.^{14,22,23}

3. The potential to learn: this means knowing what has happened and the ability to learn from experiences, including success and failure, and making sense of experiences over time. Learning is the foundation for the ability to respond, monitor, and anticipate.^{14,22,23}
4. The potential to anticipate: this means knowing what to expect or being able to prepare for what to expect^{14,22,23} of, e.g., future development, options, threats, risks, potential disruptions, and changes in work conditions or operating conditions.

These four potentials are necessary for understanding resilience in healthcare.¹⁶ However, there is also a need to develop a more detailed knowledge of the content of the potentials in everyday clinical settings, which will be addressed in this article.

Next of Kin Policy in Norway

Norwegian healthcare is a public responsibility, and the formal expectations of family members or next of kin are low.²⁴ The government has changed its next-of-kin policy to highlight them as important stakeholders for the patient and the healthcare system and should therefore be more involved.²⁵ The aims are to give attention to the relationship among the patient, next of kin, and the healthcare services to improve the quality and safety of healthcare and strengthen user involvement, including involvement of next of kin, as a legal right.²⁶

Aim and Research Question

The aims of this article are to explore the stakeholder perspective in cancer care and to generate new knowledge on how next of kin in Norwegian hospitals within the cancer care field can be co-creators of resilience in healthcare services, from the viewpoint of healthcare professionals and managers. The article explores how next of kin to patients with cancer contribute to create and maintain resilience in the chain of service provision.

The following research question guides the study: How are next of kin involved in shaping resilience within cancer care in hospitals?

The article takes the perspective of healthcare professionals and managers by revealing the awareness of the next-of-kin role in resilience at the operational level.

Methods

Design and Study Settings

The design is a case study²⁷ of two large Norwegian hospitals. The hospitals are within the same regional health authority and subject to the same national and regional policy documents. The cases have been explored at two organizational levels: clinical department managers at the meso level and multidisciplinary healthcare professionals at the micro level.

Data Collection

Thirty-two qualitative semistructured interviews were conducted in the two case hospitals for a 4-month period (December 2015–March 2016). Table 1 shows an overview of data collection for this study.

Hospital A		Hospital B	
Meso level (managers)		Meso level (managers)	
Consultant	1	Consultant	2
Nurse	2	Nurse	—
Oncology nurse	3	Oncology nurse	4
Quality manager	1	Quality manager	—
Micro level (healthcare professionals)		Micro level (healthcare professionals)	
Consultant	2	Consultant	2
Nurse	4	Nurse	2
Oncology nurse	3	Oncology nurse	6
Total	16	Total	16

TABLE 1: Overview of the Data Collection

The interviews were based on an interview guide inspired by Bate et al.²⁸ The questions were related to the structure, politics, culture, education, emotions, and physical and technological challenges of the organizing for next of kin involvement. In addition, questions covered next-of-kin role and contribution to quality and patient safety, e.g., “What is the role of next of kin to cancer patient in your work place? How do next of kin contribute to

quality and safety of cancer patients?; How do healthcare professionals consider next of kin who are speaking up about quality or patient safety concerns?" The data collection is described more closely by Bergerød et al (2018).⁶

Ethics Approval and Consent to Participate

The study has been acknowledged by the Regional Committee for Medicine and Health Research Ethics in Norway (2015/1488). Participation is based on voluntary recruitment and written informed consent. In accordance with the requirements in the Personal Data Act, the project has been approved by the data protection officers at the two hospitals.

Analysis

All interviews were transcribed and the data were analyzed by a directed content analysis according to Hsieh and Shannon (2005)²⁹ guided by the RHC framework for resilient performance,^{15,22} and the four potentials of respond, monitor, anticipate, and learn. Through our analysis, we developed identified resilience-shaping factors by analysis of the content in cancer care focusing on the role of next of kin as stakeholders. All authors read the transcribed interviews and contributed to the analysis. I.J.B. led the analytical work in discussions with G.S.B. and S.W. on how to categorize the data according to the four resilience potentials.

Results

The results are presented according to the RHC framework and the four potentials for resilient performance.^{15,16,22} Under each heading, we include mechanisms where next of kin contribute as resilience-shaping factors.

The Potential to Respond

Next of Kin's Ability to Observe Guides Care Decisions-Makers' Response

The health professionals in this study highlight next of kin as important stakeholders in helping them respond more quickly to change in patient condition, because of their observations. Results show that healthcare

professionals do not always know if it is safe for the patient to go home between treatments. If the patients, e.g., live with their next of kin, they are more likely to be discharged because they have someone who can observe and respond in case of adverse events such as fever, bleeding, or other discomfort related to the treatment or illness. In these situations, next of kin are often referred to as equally or more important than other healthcare personnel in the municipality.

We discharge many patients who are very ill. For example, when there is a compression fracture in the column, we are afraid of threatening cross-sectional lesion or patients on chemotherapy that have to come to the hospital rapidly if they experience fever. They [next of kin] are widely utilized. It is very often that we miss it when next of kin are not present.

(Consultant, hospital A)

Next of kin often guide healthcare professionals in making care decisions. The findings show that observations from next of kin provide important knowledge and insight into how capable the patients are of handling the burden and adverse effects of treatment. When next of kin are involved, they often give healthcare professionals important information that can help understand the patient's condition. This information can be crucial for deciding further treatment or changing the care plan.

Lastly, I participated in rounds with a preterminal patient, who, even though she was awake and perceived as being clear and oriented, did not make sense of pain. She had a serious infection and pneumonia, and we tried to ask her if there was a change in the condition concerning cough or breathing. Then the husband could tell us that her breathing had become worse and that he felt she was breathing more heavily. This happens quite often.

(Consultant, hospital A)

Dependency of Next of Kin in Daily Care to Respond Quickly

Managers and healthcare professionals claim to depend on next of kin to give the patient safe and high-quality care. Next of kin perform important

care tasks, e.g., if the patient needs to be fed or is uncomfortable. These tasks often require the staff to be with the patient for a long time. On shifts with low staffing, next of kin are often the “pieces of the puzzle” that help managers and staff complete all tasks required of them by internal and external stakeholders (e.g., other patients, management, wards, or colleagues). This next of kin empowerment enables the staff to respond more quickly to patients who do not have their next of kin at bedside.

The Potential to Monitor

Next of Kin Watch Over Medication and Nutrition in Patient Care

The next of kin are assigned daily tasks either by the patient or healthcare professionals related to monitoring the patient's medication for pain treatment, nutrition, and daily care.

They [next of kin] often help to transport the patient, follow the patient to take blood samples, check the medical list, and also ensure that the patient takes the medication at the right time, especially if the patient doesn't want homecare. They inject medications, measure temperature and contact the hospital if the patient experiences fever. They [next of kin] have a huge sense of responsibility for the patient and are resource persons for the patient, us (hospital), and the municipalities.

(Nurse, hospital A)

Healthcare professionals describe how next of kin have in-depth knowledge about the patient including how he/she was before the cancer diagnosis. For example, if the patient had poor appetite, a next of kin will sometimes know better than a nurse what the patient would eat and is often a good resource in encouraging the patient to eat.

Next of Kin Oversee Patient Activity Level

Physical activity and rehabilitation before new treatment are another area where next of kin's ability to monitor the patient is highlighted. Next of kin are often considered to have the capacity and motivation to contribute something extra during patient visits. Healthcare professionals often suggest that next of kin can help the patient with daily activities or physical

activity by, e.g., taking the patient for a walk. In the hospital, this should be voluntary, but when the patient is at home between treatments, the expectation of next of kin's contribution to daily care is more explicit.

Watching Patient Signals in Palliative and Terminal Care

Healthcare professionals note that next of kin often are important partners in monitoring palliative and terminal care. Next of kin's involvement seemed to be more obvious and legitimized in this area. Healthcare professionals often work in close collaboration with next of kin in terminal care. In this stage, healthcare professionals learn and inform next of kin what to look for in the patient's condition, how to care for the patient by, e.g., moisturizing the mouth or observing if the patients are in pain or discomfort. The next of kin's perceptions are considered when the patient's condition changes. Healthcare professionals and next of kin often have different views and expectations of what is in the patient's best interest. This disparity is most pronounced in what poses a potential risk to the patient. A lack of involvement of next of kin perceptions and expertise may result in an adverse outcome:

Then one evening the patient became very ill. There was a lot of medication and people all over the place. The problem was not lack of resources. The next of kin perceived that the patient was dying, and she probably was. This was not conveyed. There was so much turmoil that they [next of kin] felt overlooked. They went home. That night the patient died alone.

(Consultant, hospital B)

The Potential to Learn

Key Role for Safe Transitions Across Care Levels

As we saw in the next of kin potential to monitor, the potential to learn highlights next of kin's experiences and perceptions of the patient condition as important features of the hospital's ability to provide safe cancer care. Results show that the next of kin have a key role that cannot be fully replaced by other stakeholders or hospital staff in terms of making sense of experiences for safe transitions and incorporating informal learning processes between service levels. Next of kin contribute to healthcare services by helping the patient between home and hospital and with

transfers between care levels within the hospital. Next of kin often hold and share important experiences that help healthcare professionals in improving their services by learning more about the patient's previous condition and history. Healthcare professionals describe the importance of continuity of care among healthcare professionals for building a close and collaborative relationship among all stakeholders to adjust and learn from next of kin's perceptions and experiences.

I think it's an assurance for next of kin that they meet the same nurses. Next of kin seem to report more of the actual patient condition when they meet the same nurses.

(Quality manager, hospital B)

In addition, next of kin often take a questioning role and thereby contribute to stronger vigilance among the healthcare professionals about issues such as medications and injection rates. Results indicate that healthcare professionals may detect failures sooner and avoid adverse events because of reminders from next of kin.

The Potential to Anticipate

Next of Kin Are Foreseeing Possible Deteriorations and Treatment Consequences

In this study, the potential to anticipate is highlighted as an area for growth and more systematic investigation. This study finds two important mechanisms that are essential for the potential for anticipating: (1) how healthcare professionals involve next of kin to understand the possible consequences of treatment and care and (2) how healthcare professionals enable next of kin to foresee and handle adverse events and possible deterioration in the patient's health.

In the two hospitals, we found no systematic next-of-kin involvement or special training for next of kin even if they were performing tasks requiring special training and skills:

A next of kin approached me today and said, "We feel so alone in this. We control things that we cannot really do. We provide injections and do things we do not have education to do."

(Consultant hospital B)

Healthcare professionals describe often asking the next of kin to observe the patient over time, report changes in the patient's condition, assist the patient with daily care, bring food or drinks to the patient, feed the patient, and share information that can prevent adverse events and enhance the quality of care. Next of kin are often a unique and invaluable resource for quality and safety of cancer care. One of the most appreciated features of next of kin involvement is the ability to motivate the patient and to share information about the patient.

...the most important contribution from next of kin is the dissemination of information at the doctor's or nurse consultations. [...] Next of kin have a greater ability to understand because they are there for the patient while the patient has more than enough with himself.

(Manager, hospital B)

The division of work seems to come naturally because of the close relationship between the next of kin and the patient, but it also causes challenges. In both hospitals, there was confusion about what the next of kin could be asked to do and what role the next of kin should have in hospital cancer care. This is in contrast to the finding that the next of kin have a coordinating function in cancer care.

This result indicates that the hospital cancer care would benefit from a more systematic approach to next-of-kin involvement, enabling them to act promptly in light of the possible consequences of treatment and care by teaching them what to expect. Next-of-kin involvement may also strengthen the reflective processes around the patient by introducing viewpoints and observations that are not readily accessible to the health personnel, e.g., what the patient's life was like before the cancer diagnosis.

Discussion

Theory Development: Next of Kin Performance in Resilience

Hollnagel²² argues that resilience performance in organizations can be understood through the four resilience potentials. Moreover, Hollnagel²² argues that if the organization lacks these potentials, it will be incapable of resilient performance. Our findings indicate that next of kin constitute a new potential that supports the other four. Weakness in monitoring, learning, anticipating, and responding in a clinical setting can be prevented by the use of next-of-kin information, observation, and task performance, as shown in this study. This depends on collaboration between the next of kin or other key stakeholders around the patient, implying that a stakeholder analysis early in the cancer trajectory could make it easier for healthcare professionals and managers to take advantage of their information and skills in patient care.

This study brings a new aspect to the operationalization of the resilience potentials in hospital cancer care by describing healthcare professionals' and managers' view on next-of-kin role in the trajectory of cancer care. This study offers new knowledge on how next of kin are co-creators of resilience. The resilience healthcare theory and the potentials for resilient performance have been criticized for lacking descriptions and clarity of conceptual links between theory and everyday practice in complex systems.³⁰⁻³² This study contributes to a better understanding of resilience in a stakeholder perspective, by bringing context-specific and clinically relevant content into the four potentials for resilient performance in hospital cancer care.²² In our view, these potentials need further operationalization. The RHC theory could benefit from more studies to refine key constructs in the potentials and position resilience into everyday practice across organizational levels. This may give a deeper understanding of different contextual settings and a foundation for interventions in healthcare organizations.

The Stakeholder Potential: A Key Piece of the Puzzle

In both cancer care departments, we found a close, interactive, and collaborative relationship among healthcare professionals, the patient, and

next of kin. The next of kin held a key role as safety experts. Healthcare professionals describe next of kin as important stakeholders contributing to patient safety by, e.g., helping them respond more quickly to changes in the patient's condition and by sharing important information in decision-making to ensure the best quality of treatment.

Next of kin complement healthcare professionals in all four potentials for resilient performance by their unique insights and responses. The close relationship seems to be a prerequisite for healthcare professionals' adaptations in patient care during disruptions and challenges. The healthcare professionals in our study identified nine areas in which next of kin are important resources in improving quality and safety. Similar to O'Hara et al¹⁸ talking about the family as part of scaffolding the system and the study by Fyland et al³³ showing that patients are an underrecognized resource in system resilience, our study shows that next of kin are a key resource in nine areas of system resilience in the cancer trajectory. Figure 1 gives an overview of next of kin's contribution to the four potentials in hospital cancer care. These nine areas were common across the two hospitals' cancer care departments.

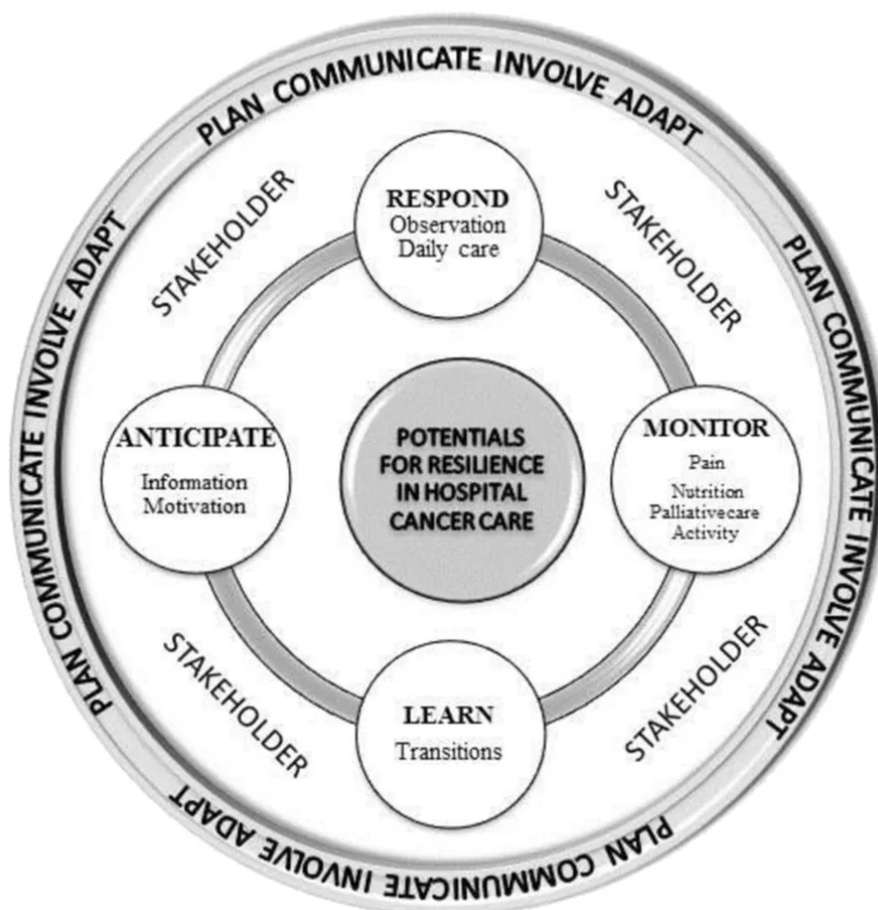


FIGURE 1: Next of kin contribution in hospital cancer care.

This study offers several descriptions of healthcare professionals' dependence on next of kin as a practical resource with unique insight in cancer care.⁶ At the most difficult times, healthcare professionals often used next of kin to perform some tasks. In these situations, next of kin functioned as safety resources that compensated for the hospital staff's shortfalls, e.g., by calming an anxious patient, feeding, noting changes, or providing daily care. When the organization lacked capacity, next of kin became the piece of the puzzle that helped healthcare professionals provide sound care despite heavy workload, understaffing, or other potential threats to patient safety.

At first glance, this seems to be a rational decision when there is a high risk of adverse events and it is difficult for healthcare professionals to provide sound patient care. On the one hand, this could be taken as a success story for resilient performance. On the other hand, taking into account studies highlighting the many burdens next-of-kin shoulder,^{12,34} it is important to understand the potential burdens for stakeholders. Failure in communication and lack of involvement of next of kin are among the top 16 patient safety hazards in Norwegian cancer care.³⁵

Although the structure depicted in Figure 1 shows similarities with the traditional layout of Deming's circle, it should not be apprehended in a mechanical way.³⁶ From a clinical perspective, monitoring often precedes responding. Therefore, it seems rational to describe the elements as potentials, not as processes. A possible fifth potential, allowing for active involvement of patients and next of kin, could therefore be to expand the model to include a potential for stakeholder involvement and collaboration. However, there is a need to plan, communicate, and make adjustments in the involvement process, as depicted in Figure 1. This will apply to all the four potentials and could possibly form the basis as a prerequisite for other contexts. Hollnagel²² has asked whether there is need for additional potentials such as planning, communication, and adaptation. Our suggestion of stakeholder involvement as a potential may not meet Hollnagel's criterion of potentials as functions in organizations,²² but a stronger understanding of the stakeholder perspective and a more systematic analysis and involvement of the patient (e.g., the study by Fylan

et al³³) and the stakeholders will strengthen the possibilities of operationalizing resilience in different clinical settings.¹⁸

The findings in this study indicate a divergence between how healthcare professionals use next of kin as a practical resource in practice and their ideal involvement with next of kin. Ideally, next of kin should participate in patient care on their own terms and not because of, e.g., a lack of hospital capacity. In Resilient Health Care theory, this difference is described as “work-as-imagined” and “work-as-done.”¹⁶ Healthcare professionals adjust to variations in situations and take advantage of next of kin competence for care tasks and observations but at the same time struggle with the accompanying emotional stress. This shows how healthcare professionals involve next of kin in their trade-offs to provide sound care quality.³⁷ Findings tied to work-as-imagined versus work-as-done and professional trade-offs also indicate that more attention should be given to the emotional stress that healthcare professionals experience to ensure that the stress does not drift into risk of failure and adverse events for patients with cancer.^{38,39}

This study raises questions about next of kin involvement in cancer care and how to develop and cultivate teams around the patient that acknowledge the next of kin as co-creators of resilience. Resilience in this view requires learning from next of kin experiences; a set of skills to understand how next of kin as a practical resource contributes to the operational performance; find a balance between involvement and burden for next of kin; and, most importantly, acknowledge that next of kin, when involved, has the potential to enhance the quality and safety of patients with cancer.^{6,18}

Limitations

First of all, when categorizing the data into the predefined categories of responding, monitoring, learning, and anticipation, we found examples where the categories appeared overlapping. This problem has been experienced by others,⁴⁰ and to ensure trustworthiness in the analysis, all three authors contributed in the analytical process and discussed potential challenges. Secondly, there may be variations across organizational levels (meso, micro) and between the hospitals in how next of kin contribute to

cancer care, which cannot be detected by this study. However, because our data material was consistent between the studied entities here, we have chosen not to discuss this in our article. Still, we believe that there is a potential in exploring the differences between professional groups and between managers and healthcare professionals in how they consider the contribution from next of kin as co-creators of resilience.

Conclusions

Next of kin complement healthcare professionals in all four potentials for resilient performance (respond, monitor, anticipate, and learn). In this study, we suggest a further development of Hollnagel's four potentials for resilient performance.²² This development can be considered a stakeholder potential that emerged through descriptions of how next of kin contribute to the provision of sound patient care under challenging conditions, possibly by expanding the RHC framework to include a potential for stakeholder involvement and collaboration. We demonstrate this in identifying nine areas in which next of kin co-create resilience. Moreover, further studies are needed to explore the stakeholder potential beyond next of kin (e.g., Fylan et al³³), to generate new knowledge about how different stakeholders around the patient collaborate in and contribute to shaping resilience.

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