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# Hospital social workers' contributions to increasing health literacy among parents of acutely and critically ill children

## Sykehussosionomers bidrag til å styrke helsekompetanse hos foreldre til akutt og kritisk syke barn

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### ABSTRACT

Hospital social workers often engage in health literacy activities to support patients' and families' functioning and adjustment to illness, but social work literature has seldom used health literacy terminology. This paper reports on a qualitative study of paediatric hospital social workers' understanding of the needs of parents with acutely ill children and how their contributions may accommodate these needs to strengthen parental health literacy. Utilising systematic text condensation, the study reveals four themes: (1) understanding of medical information, (2) counselling and service coordination, (3) emotional needs, and (4) timing of information. The findings suggest that hospital social workers make valuable additions to health literacy.

### SAMMENDRAG

Sykehussosionomer jobber med å fremme sykdomsmestring hos pasienter og deres familier. Sette arbeidet har i liten grad blitt omtalt som et bidrag til å styrke helsekompetansen til pasienter og pårørende. Artikkelen bygger på en kvalitativ studie med pediatriiske sykehussosionomer, om deres forståelse av foreldres behov når et barn er akutt og kritisk sykt, og hvordan de møter disse behovene på måter som kan bidra til å styrke foreldrenes helsekompetanse. Det har blitt benyttet Systematisk tekstkondensering som analysemetode for å komme frem til fire temaer; (1) å forstå medisinsk informasjon, (2) veiledning og koordinering av tjenester, (3) følelsesmessige behov, og (4) timing av informasjon. Funnene støtter opp om at sykehussosionomenes arbeid kan bidra til å styrke pasienter og pårørendes helsekompetanse. Deres helhetlige tilnærming kan utgjøre verdifulle bidra til helsekompetansefeltet.

### KEYWORDS



Hospital social work; health literacy; parental needs; paediatric; acute

### NØKKELOD

Sosialt arbeid på sykehus; helsekompetanse; foreldrebehov; pediatri; akutt

## Introduction

Health literacy has become an area of increasing interest for policymakers and an important concept in health care that helps to increase efficiency and reduce health expenditures (Eichler et al., 2009;

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Haun et al., 2015). Health literacy is acknowledged as a critical determinant of health by the World Health Organization and is referred to as ‘the personal and relational factors that affect a person’s ability to acquire, understand and use information about health and health services’ (Batterham et al., 2016). Low health literacy has an impact on poor health outcomes (Nutbeam, 2000; Sorensen et al., 2012) and is interlinked with social disadvantages – such as low levels of education and income – and immigration status (Beauchamp et al., 2015; Bo et al., 2014; Paasche-Orlow & Wolf, 2007). The complexity of health organisations may affect how individuals access and engage with information and health care. This interaction promotes health care organisations’ responsibility to improve their health literacy responsiveness to individual health literacy needs (Herndon et al., 2011). To be able to meet individual health literacy needs, however, a focus expanded beyond health communication and health education, which recognises the importance of social, economic, and environmental conditions, is required (Nutbeam, 2000; Sorensen et al., 2012).

For more than a century, hospital social workers have often engaged in health literacy activities with patients and families (Findley, 2015; Liechty, 2011). Yet, social work literature seldom uses health literacy terminology to describe hospital social work. Nor has social work contributed much to health literacy research. The concern about the connection between low health literacy and social disadvantages should indicate a great potential for a productive alignment between social work theory and health literacy (Liechty, 2011). For instance, the ecosystemic person-in-environment framework (Hamilton, 1951), characterising social work, could provide a broader understanding of factors on different levels that influence patients’ and families’ health literacy by accounting for the complexity of the interaction between the individual and his or her environment (Green & McDermott, 2010). Furthermore, combining different theories and models with the person-in-environment framework may allow for expanded understandings of complex social and human mechanisms. One example may be the psychological trauma model’s *window of tolerance* (Siegel, 1999), which can be used to better understand how stress caused by social and medical conditions can have an impact on patients’ and families’ health literacy. The window of tolerance is used to describe the zone of arousal, the space where a person is able to function most effectively, which affects the ability to readily receive, process, and integrate information (Corrigan et al., 2011).

Empirical studies suggest that children’s health outcomes may be related to parental health literacy (de Buhr & Tannen, 2020; DeWalt et al., 2007; DeWalt & Hink, 2009; Sanders et al., 2009; Yin et al., 2007). The literature has shown that parents with low health literacy, compared to parents with a higher level, have less health knowledge and demonstrate health behaviours that are less beneficial to the child’s health (DeWalt & Hink, 2009). Parental health literacy skills are particularly important in acute and critical situations where they often must process information about complex conditions and make critical decisions rapidly (Herndon et al., 2011). However, the relationship between limited parental health literacy and poor health outcomes can be influenced by health care variables and the interaction between a provider and the parents (Chisholm-Burns et al., 2018; Wilder et al., 2016). Health care providers’ responsiveness to patients’ needs has proven integral to compensating for limited health literacy (Farmanova et al., 2018).

During the last few decades an increasing number of studies on the association between parental health literacy and a child’s health have been published (de Buhr & Tannen, 2020). However, to the best of our knowledge there is a lack of research exploring how hospital social workers’ in general and paediatric hospital social workers specifically contribute to strengthening parental health literacy. To address this gap, we asked the following research questions: (1) How do hospital social workers in acute paediatric care understand parents’ needs? and (2) How do they describe their contribution to these needs in ways that might strengthen parental health literacy?

## Background

As part of hospital-based interprofessional teams, hospital social workers work collaboratively to provide psychosocial support and counselling to patients and families to adjust to their situations,

supporting their ability to cope with the practical, psychosocial and economic issues connected to an illness (Craig et al., 2015; McLaughlin, 2016; Muskat et al., 2017). In Norway, there is no general regulation of work tasks for hospital social workers. However, the Norwegian Union of Social Workers (FO) has on its website described that central hospital social worker tasks are to provide psychosocial support and counselling to strengthen patients and their next of kin's ability to cope with the situation by seeing the person with the diagnosis in a social context. The approach is aimed at conditions where the disease leads to psychological reactions for patients and relatives and where living-condition factors such as income, work, education and housing are affected. The tasks often include collaboration with municipal services and user organisations, but the main working method is the individual encounters (FO, n.d.). This description reflects the main features of hospital social workers' role performance, although the lack of common state guidelines allows for individual differences.

The description of hospital social work in Norway does not differ significantly from previous international studies that have examined hospital social workers' key interventions. In general, hospital social workers' interventions are found to be 'personalised, carefully constructed and formulated to fit' emergent and existing unique needs of each patient and family (Muskat et al., 2017, p. 773). Identifying the level of support, assessment of emotional and psychosocial needs, financial and practical needs and the need for coordination of services is central (Lilliehorn et al., 2019; Muskat et al., 2017; Pockett et al., 2020; Wiggins et al., 2018). In their study, Pockett et al. (2020) found that psychosocial assessment was the most frequent intervention among Australian oncological social workers. Providing emotional support and family-oriented care (i.e. crisis intervention, bereavement counselling, techniques such as active listening and reframing) to patients and families at times of crisis in order to reduce distress has also been emphasised by other researchers (Craig et al., 2015; Judd & Sheffield, 2010; Lilliehorn et al., 2019; Wiggins et al., 2018). Other important hospital social work interventions seem to be practical interventions, such as providing financial resources and connecting with community resources (Muskat et al., 2017). Existing literature refers to having an ill child entailing significant costs (Craig & Muskat, 2013; Keefe et al., 2009; Moon et al., 2019; Muskat et al., 2017), and reduced income caused by the need for full-time caregiving (Muskat et al., 2017). The hospital social worker's role in financial counselling and guiding to supplementary income thus stands out as an essential part of the overall role, especially for families with financial challenges (Muskat et al., 2017). The advocacy role the hospital social worker undertakes with community services and organisations facilitates the patient's transition from the hospital to the community (Judd & Sheffield, 2010). Communicating, mediating or advocating with the medical treatment team on the behalf of patients and families when they are dissatisfied with the treatment or in conflicts with the team increases patients and families' experiences of support (Wiggins et al., 2018).

## Materials and methods

### Design

This article draws on a qualitative study that explored hospital social workers' experiences working with parents of acutely and critical ill children. To explore in depth the individuals' unique understandings and experiences, semi-structured individual interviews were considered appropriate (Charmaz, 2006). The interview approach was based on the premise of social interaction as a way to generate data.

### Recruitment and respondents

The inclusion criterion was that participants were educated social workers and in direct practice roles in paediatric acute wards. Twenty-four social workers were identified among 17 hospitals in Norway

that had paediatric wards. The participants were recruited through an email sent to their superior. To ensure the participants' anonymity and volunteer participation, the response to the invitation was returned directly to the researcher. All participants completed informed consent forms.

### **Data collection**

The interviews were conducted between May and October 2019. Each interview was conducted in Norwegian and lasted between 56 and 90 minutes, with an average of 72 minutes. Questions from a semi-structured interview guide were used, not in a specific order but adapted to answers provided by the participants. The interviews mainly took place at the participant's workplace. For practical reasons one participant was interviewed over the telephone. All interviews were recorded and transcribed verbatim. The interview quotes were translated by the first writer and reviewed by a colleague. The software NVIVO 12 Pro was used to manage data. The project was approved by the Norwegian Center for Research Data 04.02.19 (ref. no. 150884).

### **Data analysis**

The interviews and the main analysis were conducted by the first author. The data were analysed using the four-step process from Malterud's systematic text condensation (Malterud, 2012). Based on general impressions in the initial step, the transcriptions were coded into 11 identified themes. Each code group was subjected to abstraction by condensing the content and recontextualized by summarisation as generalised descriptions. By working with these analytic texts, a close connection between several of them was recognised and led to a merging into three final code groups. The findings presented in this study are four themes from one of the code groups, called *descriptions of needs and contributions*. The themes are *understanding of medical information, counselling and service coordination, emotional needs, and timing the information*.

## **Findings**

Out of 24 hospital social workers invited to participate in the study, 19, representing 12 hospitals, responded positively. Three rejected the invitation and two did not respond. The participants were Scandinavian women with an average age of 49.5 years (35–68). Their average hospital seniority was 12 years (1–35 years) and average duration of their seniority was 24.6 years (13–42 years). Seventeen of the nineteen social workers held a master's degree or had additional training beyond a bachelor's degree in social work.

The following presentation of each theme starts with the social workers' understanding of parental needs (A) followed by their description of their contribution to these needs (B).

### **Understanding of medical information**

#### **Parents' need to understand medical information**

An important parental need, according to the participants, concerned the need to understand medical information. Parents' lack of understanding is challenging, as they struggle to get a sense of control of the situation and experience predictability. According to the social workers, unfamiliar medical terms may reduce parents' understanding of their child's medical condition and situation. The participants reported becoming aware of this challenge in various situations. Generally, parents directly expressed how they understood the medical information:

Some say, 'They [the physicians] were very good at explaining and I had time to ask' But some say, 'Honestly, I didn't understand much of what they said'. (SW18)

Other times it was expressed indirectly, as when a social worker was helping a parent fill out an application and revealed an understanding of the sons' newly diagnosed diabetes as fatal. Other situations concerned poor language proficiencies, where the use of an interpreter represented vulnerability to incomplete understanding. This was illustrated by a conversation where a doctor told the parents that their child would not survive. When the parents reacted with a smile, it was obvious that the interpreter had failed to convey the actual message.

Some of the participants occasionally experienced how parents with alternative perceptions challenged the established knowledge on children's needs. An example may be about not providing age-appropriate information about the disease in the hope of protecting the child.

### *Social workers' contribution to identifying medical information needs*

Social workers' assessments of medical information needs were related to their professional knowledge acquired through several years of experience in hospital practice. Most participants pointed out the value of this experience when preparing for and meeting with parents. The social workers' accumulated insights into medical matters were essential for how they used the medical situation as an opportunity to establish contact. One opening phrase could be 'what do you know about further treatment?'. Parents' answer to this question provided a chance to assess parents understanding of the medical situation.

Drawing on experiences that understanding can affect how parents inform a sick child and their siblings, the social workers found that ensuring adequate understanding was important. A majority of the social workers saw it as part of their task to support parents in this manner. At the same time the social workers emphasised their non-medical role, avoiding disclosure of medical information not yet provided by their physician:

So I am very careful to ... or that's for the parents themselves to say. Because if I say something wrong there, that the child is maybe going to have radiation, and then ... oh no, they haven't heard anything about it. Right? Then I just cause them anxiety and worries. (SW10)

Using their medical understanding, however, the social workers could formulate adequate questions without conveying unknown medical information.

A large proportion of the participants talked about how they met parents' need for advice regarding what information to give the child or their sibling(s), ways of talking, and useful words. As one social worker explained,

You don't have to say everything, but what you say must be true. Because kids, they just catch things, and fill in the rest with their imagination, and what they imagine can often be much worse than reality. (SW12)

Usually the social workers noticed it was sufficient to make parents aware of children's needs. But some found this was not enough to change parents' perceptions about not informing their children about a diagnosis and prognosis. One of the social workers problematised the extent to which they should tolerate views that deviated from established knowledge.

### *Counselling and service coordination*

#### *Parents' need for financial and social rights' information and coordination of services*

Social workers often found parents' knowledge of financial and social rights and coordination of services regarding severe illness to be limited. The parents needed to be informed about basic rights assured by the Norwegian welfare state, like sick leave related to sick children, securing income during hospitalisation, and coverage of expenses for medicines and transport. Many parents needed advice and help with organising care of siblings. As one participant put it,

When you are in crisis, you are less able to sort things out, in a way. Yes, how to go about it. (SW3)

The social workers pointed to financial concerns, overwhelming emotions, and a lack of knowledge about the health care system as factors that may increase the need for support. Insufficient language skills further increased vulnerability:

One thing is if you don't know the language. But if you have no knowledge of the Norwegian system at all, then this is a difficult welfare system to explain, I think. They don't have the same words either, even if you use an interpreter; there are no words for those things. (SW3)

### ***Social workers' contribution to identifying the need for financial and social rights' information and service coordination***

The social workers considered providing access to resources to be one of their main tasks. Even if parents did not raise the issue, the social workers saw it as their responsibility to make parents aware of possibilities:

We know what we should be doing, and we know what they are entitled to, so they don't have to wonder ... and spend their energy on that. (SW12)

For some parents a great deal of help was required from the social worker, such as establishing contact with service offices, filling out application forms, and contacting their employer to make them aware of their responsibility. Sometimes help with housing or access to daycare for siblings were provided to benefit the ill child. However, it varied to what extent social workers offered extended services beyond issues directly related to hospitalisation. Assessments of the extent to which they should provide these services were challenging dilemmas for the social workers.

Another task could be to advocate internally for sick leave. One social worker referred to a conversation between her and a physician about sick leave for a parent:

Then I say, 'You have to. They get no money.' Then he says, 'No money?' I, 'No, they have no money in their account.' (SW18)

The social workers were often contacted several times by the same parents as someone who knew their story and might accommodate their needs. Within a context dominated by a lack of staff continuity, stability was something most of the participants expressed as significant for reducing parents' stress during a child's hospitalisation. In addition, to increase parents' sense of control by sorting out what should be handled was perceived as way of reducing stress:

When you have the practical things sorted out, that 'this is ok, this is what you do, I will do this, together we'll get it done', then I feel like they can breathe again. (SW1)

## ***Emotional needs***

### ***Emotional needs as parents***

According to several of the social workers, a sick child and their siblings also need safety, sufficient information, and emotional support. Many parents expressed concerns about their children's reactions and the consequences of illness for the future. Therefore, they sought the social workers' advice on how to best meet children's needs:

They want to do the right things, or they want to say the right things, or they are really scared of doing something wrong. (SW17)

Other parents wished to be strengthened in their caring role. Social workers observed how parents' concerns effected their ability to take the child's perspective. The strange and unknown situation in which parents are supposed to manage appeared in different ways for the parents. The social workers experienced that while some parents seemed to be practically oriented and focused on organising, others were deeply affected by concerns regarding the sick child, siblings, or emotional reactions within themselves or from their partner. Participants also saw that most parents were pre-occupied with the sick child and their siblings at the expense of their own or the couple's needs.



### ***Social workers' contribution to emotional needs***

The social workers in the study seldom interacted directly with the sick child or their siblings. However, many saw it as their job to help with parenting. As one participant said,

Try to make them aware of the child and say that you are important. 'Now you are the important ones here' and reassure them that they can get through it together. (SW17)

Those working directly with children reflected on being a role model for parents on how to respond to their child. By modelling how to follow the child's focus and pay attention to their words or actions, they wanted to strengthen the parents' ability to take the child's perspective. These social workers also helped parents develop an ability to protect their child from being forced into medical situations with a potential traumatising effect, creating an awareness of parental responsibility to ensure their child's voice, thoughts, and feelings were taken seriously.

Another important issue concerned communication and support of parents regarding siblings' emotional reactions to the situation. Normalising the diversity of reactions seemed to be a common way of addressing concerns. By referring to experiences with different reactions and ways of meeting their emotional needs, the social workers intended to reduce worries and increase the parents' confidence in how they would best support their children.

The social workers emphasised the importance of accepting that the situation was difficult for the entire family. Many parents needed to hear for themselves that their reactions were not abnormal. Similarly, some of the participants were concerned with improving couple's understanding of each other's reactions by supporting them in sharing their feelings. In doing so, they saw parents gaining a better understanding of each other, which strengthened the couple's ability to stand together in a critical situation. According to the social workers, offering support in getting through the weeks at the hospital provided parents with useful experiences to build upon when they returned home.

### ***Timing the information***

#### ***Parents' need of timed information***

A fourth theme emerging from the analysis concerns the timing of information and how timing affected the parents' ability to perceive information. Disruptions or the expectation of disruptions, recently received or the expectation of crucial medical information, or parental concerns about their child while interacting with the social worker were all examples of factors that could affect the parents' attention. Often it was the total amount of stress that challenged parents' ability to concentrate on receiving and understanding vital information:

A lot of the information they get in the beginning [at another hospital], they say they have forgotten almost everything people told them there. Because they've been a bit out of it ... They feel totally at a loss then, so they say, 'we really don't remember anything.' (SW17)

Parents' lack of information recall did not suggest a lack of interest in receiving information at that stage, according to the social workers. While waiting for the child to be diagnosed, many parents wanted to be informed about potential rights and services. To focus on something concrete seemed to be helpful in an otherwise confusing situation. Others stated explicitly they did not want the information before the situation was clarified properly.

#### ***Social workers' timing of information***

The social workers' reflections on timing were based on several sources of knowledge, such as crisis theory, their own experiences, and their assessment of the actual situation. As one said, sometimes there were limitations on what is possible to comprehend:

You know this through working with crisis, people cannot deal with everything at once, and there are limits to what they can grasp. (SW15)



Several highlighted the importance of being flexible about the consultation timing with parents. Before initiating a consultation, they considered whether the planned consultation would create additional stress or prove helpful. Flexibility was also necessary during the consultation if, for instance, the consultation was interrupted, and the social worker had to return another day.

All the social workers stressed the necessity of identifying parents' needs and considering what information should be given. At the same time, most talked about the importance of being sensitive to parents' needs in the moment. The ongoing assessment of what focus the conversation should have, was expressed this way:

Well, it can be that you have made a plan about what to say and stuff, and then it doesn't turn out like that at all because they are concerned about something completely different. (SW11)

Keeping track of parents' needs to determine the direction and content of the consultation seemed to be a governing factor for most of the social workers. Their assessment could be based on small signals from the parents, such as facial appearances and expressions, or the atmosphere in the room. Other signals could be body stress or them checking the time. One participant emphasised the importance of professional experience and intuition in identifying minor signals conveyed by patients or parents. Some of the social workers verified their assumptions by asking questions like 'what do you need the most right now?'

## Discussion

The aim of this study was to explore how hospital social workers in paediatric acute care understood parents' needs and how they described their contribution to these needs in ways that might strengthen health literacy in parents. The findings support a relationship between perceived needs and interventions providing vital knowledge about health literacy promotion and accommodation activities (i.e. facilitating understanding of medical information, providing knowledge and access to rights and services and giving emotional support). Being flexible towards unique needs in terms of the timing and content of consultations seemed to be crucial for performing their role.

Previous social work research has highlighted the need for clear communication between the treating teams, patients and their families (Craig et al., 2015; Moon et al., 2019; Muskat et al., 2017). However, the literature has elaborated on the hospital social worker's role in this activity to a limited extent. The findings in this study suggest that they have a central role in recognising parents' medical information needs and misunderstandings. Representing an alternative to medical jargon, they facilitate communication and enable different modes of expression. By talking about medical conditions directly as part of establishing contact or indirectly in the context of resource searches, they create an opportunity to gain clarity on parents' lack of or incorrect understanding. Health literacy literature indicates that the increasing complexity of paediatric healthcare raises greater demands on patients and parents' health literacy (Beauchamp et al., 2015). It also suggests that different language needs, social and cultural backgrounds or cognitive abilities may not be addressed by complex healthcare organisations (Wynia & Osborn, 2010). This underpins the necessity of hospital social workers' role within those organisations in mitigating the negative consequences of low health literacy. This function coincides with the core of health literacy by increasing the ability to gain access to and understand information (Nutbeam, 1998).

As mentioned, to be able to meet individual health literacy needs, a focus expanded beyond health communication and health education is required (Nutbeam, 1998; Sorensen et al., 2012). Recognising the importance of social and economic conditions is in line with the World Health Organization's definition of health literacy, which emphasises the importance of building on the patients and families' genuine needs (Nutbeam, 1998). Providing adequate material resources and ensuring relevant information on services and rights were consistently expressed as core tasks among the participants. This is comparable to existing literature that has highlighted the importance of income supplement–guidance related to the stresses associated with the increased costs of caring

for a sick child (Craig et al., 2013; Keefe et al., 2009; Moon et al., 2019; Muskat et al., 2017). Within a context where sickness costs are mainly covered by the public welfare system, it seems like parents' concerns in the acute phase are mainly related to a lack of control and knowledge of rights. This may suggest that an unpredictable financial situation is a general stress factor affecting parents.

Knowing the significance of social and economic conditions for the individual, health literacy will also call for questioning structural societal conditions that have an impact on living conditions and opportunities. However, research has shown that different national health literacy strategies mainly place the responsibility for increasing health literacy in the population on the quality of patient communication and patient engagement and education (Trezona et al., 2018). Further, our findings are consistent with previous research on hospital social work, in that the participants first and foremost emphasise performing individual interventions (Craig et al., 2013; Moon et al., 2019; Muskat et al., 2017). Based on the knowledge they gain about patients and families' social and economic conditions, hospital social workers are in a special position to recognise societal structures that maintain and reinforce social inequalities that have an impact on health conditions and individual health literacy. Therefore, there may be reason to argue that they have a special responsibility to convey their knowledge of the correlation between social disadvantage and health literacy competencies. Integrating a stronger social justice-oriented approach within hospital social work will therefore be needed to challenge healthcare systems and further develop national and international health literacy strategies. An intensified focus on the environment provides further opportunities for hospital social workers to contribute their expertise to the evolving field of health literacy.

The extent to which emotional support was an intentional intervention and an expected outcome of social support varied among the participants in this study. The majority perceived and recognised that interventions related to social and economic issues helped to reduce stress. In addition, they expressed that they intentionally used emotional support as an intrinsic intervention by putting reactions and feelings on the agenda, which agreed with previous literature (Craig et al., 2015; McLaughlin, 2016; Moon et al., 2019; Muskat et al., 2017). By helping to cope with overwhelming emotions, the social workers reported experiences of parents' increased ability to meet hospital demands. It seems that being able to handle practical and emotional concerns can increase parents' capacity to perceive and communicate around medical issues.

The trauma psychology term *window of tolerance* may be helpful in understanding this mechanism. Being within the zone of arousal affects the ability to readily receive, process and integrate information. The individual is affected by the social context and is generally more able to remain within the window when it feels safe and supportive (Corrigan et al., 2011; Siegel, 1999). Hospital social workers, in helping with practical issues and emotional needs, can help parents remain within their window of tolerance, thus helping to prevent emotional reactions from reducing their health literacy capacity. The personal element is an important part of the person-in-environment framework (Green & McDermott, 2010) and seems to be a useful framework for work supporting parents in an acute situation. This ecosystemic framework contributes to a broader understanding of factors that influence an individual's health literacy. Being aware of a present emotional condition supports the assumption that the level of health literacy may be dependent on context.

### **Opportunities for social work**

As argued by Liechty (2011), the absence of literature combining social work and health literacy is strange considering the relevance of health literacy for social work and hospital social workers' role in reducing the negative effects of low health literacy. Existing social work literature has explored hospital social workers' contribution to hospital settings in general (McLaughlin, 2016), and there is substantial literature examining the variety of roles and activities that they fulfil (Gibbons & Plath, 2006; Judd & Sheffield, 2010; Lilliehorn et al., 2019; Muskat et al., 2017).

However, researchers in the field of social work have been concerned only to a small extent about putting these tasks in the context of health literacy. They have neither used the opportunity to contribute with their expertise to the evolving field of health literacy nor strategically aligned their work with international, national and organisational priorities (Liechty, 2011).

The findings of this study demonstrate hospital social workers' potential contribution to increasing health literacy among families and patients. By relating to social and economic issues and overwhelming emotions in a context-sensitive way, they facilitate parents' ability to obtain and understand medical information and thus increase the ability to meet healthcare's demands. Concepts and theories within social work, such as the person-in-environment framework and trauma therapeutic perspectives, may help expand the concept of health literacy by focusing on the present context and how this affects patients and families. Moreover, a social worker's mandate also entails requirements to describe and report on what creates social problems. Perhaps there is a need to encourage hospital social workers to include this perspective to a greater extent as part of their work. Facilitating the individual's interaction with the healthcare system, followed by paying attention and pointing at oppressive structures, will be relevant in other social work settings as well.

Using health literacy as a framework for understanding and articulating health social work practice may contribute to clarifying the justification of hospital social workers' role and contribution. The politically driven aim of increasing people's health literacy provides hospital social workers with an opportunity to respond in an active manner, make themselves relevant and influence the development of research and practice. As mentioned, social work's theories may be supplementary within the expansion of health literacy and may be subject to further exploration. To more actively contribute to health literacy in healthcare institutions, but also within other fields of social work, there is a need to integrate health literacy with general medical knowledge and social work's contribution to healthcare into the curricula of educational institutions. This can in turn contribute to important debates for broadening the social perspective of healthcare.

### **Limitations**

This study has some limitations. The small number of participants did not permit more rigorous generalisations. Future research should therefore ensure a greater number of participants and include examination of knowledge and perceptions of health literacy. Furthermore, the perspective of the parents and their benefits from the consultations is missing. It may also be worthwhile noting that the first author, who conducted the interviews, used to hold a hospital social worker role in a university hospital. A decision was therefore made not to invite former colleagues, which reduced the number of potential participants.

### **Conclusion**

The findings from this qualitative study illuminate how hospital social workers described their contribution to increasing health literacy among families and patients and the health literacy responsiveness of hospitals. By relating to medical, social and economic issues and overwhelming emotions in a context-sensitive way, hospital social workers facilitate parents' ability to obtain and understand medical information and thus increase the ability to meet healthcare demands. Hospital social workers' role in strengthening parental health literacy has only been explored to a limited extent, which indicates a need for further research in this area. Ways of increasing individual health literacy, however, should have relevance in other fields of social work as well, both in terms of research and practice. Further, social workers should to a greater degree be aware of their responsibility to point at societal conditions that maintain and reinforce social inequalities that have an impact on individual health literacy.

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## Disclosure statement

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## Notes on contributors

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