

Swedish registered nurses' perceptions of caring for patients with intellectual and developmental disability: A qualitative descriptive study

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Abstract

Patients with intellectual and developmental disability (IDD) are often misinterpreted and misunderstood. Studies show that, in general, healthcare professionals have limited knowledge about IDD, and registered nurses (RNs) often report feeling unprepared to support this group of patients. Therefore, more knowledge about how to adequately address care for this patient group is warranted. This qualitative study employs an interpretative descriptive design to explore and describe Swedish RNs' perceptions of caring for patients with IDD, here in a home-care setting. Twenty RNs were interviewed between September 2018 and May 2019, and the resulting data were analysed through an inductive qualitative content analysis. The study adheres to consolidated criteria for reporting qualitative research (COREQ). Our analysis found that nurses' perceptions of caring for patients with an IDD could be understood from three overarching categories: *nursing held hostage in the context of care*, *care dependent on intuition and proven experience* and *contending for the patients' right to adequate care*. Our findings show that the home-care context and organisation were not adjusted to the needs of the patients. This resulted in RNs feeling unable to provide care in accordance with their professional values. They also explained that they had not mastered the available augmentative and alternative communication tools, instead using support staff as interpreters for their patients. Finally, on a daily basis, the RNs caring for this group of patients took an active stance and fought for the patients' right to receive the right care at the right time by the right person. This was particularly the case with issues involving psychiatric care.

KEYWORDS

content analysis, intellectual and development disability, interview, nurses, qualitative research

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1 | INTRODUCTION

Registered nurses (RNs) work within the framework of professional nursing and are expected to provide a diverse range of healthcare services to a varied and heterogenic group of patients (cf. Ganann et al., 2019). They are bound by a code of ethics that mandates RNs to respect all human rights, regardless of the patient's abilities or functional status (International Council of Nurses (ICN), 2012). Therefore, it is noteworthy that until recently and despite its importance, little research has examined the work and role of RNs for patients with intellectual and developmental disability (IDD) in more detail. Recent research seems to focus on parents with a child with an IDD and their experiences of hospitalisation (Mimmo et al., 2019), the transition from child to adult healthcare (Brown et al., 2019), health and social care for those with a dual diagnosis, for example, IDD and psychiatric health problems (Bakken & Sageng, 2016) or IDD, dementia and pain (Dillane & Doody, 2019), challenging behaviour associated with IDD (Axmon et al., 2018; Bigby, 2012), burn out among frontline carers of individuals with IDD (Finkelstein et al., 2018) and the education and training needs for nursing students (Burke & Cocoman, 2020; Doody et al., 2019; Furst & Salvador-Carulla, 2019; Wilson et al., 2019). Research has also shown that RNs feel unprepared to support this group of patients. Jaques et al. (2018) showed that RNs experienced anxiety when delivering care to patients with IDD because they worried that they may not be able to communicate effectively. This impacted the RNs' care competence and the quality of care delivered, with the result being that care needs were not identified and appropriately met. Their findings are supported by other studies (Desroches, 2019; Kritsotakis, 2017). Lewis et al. (2016) found that overall, healthcare professionals displayed limited knowledge of IDD; they concluded that these patients are often misinterpreted and misunderstood in care. Research has indicated that RNs who are educated about IDD are better equipped to provide safe and good quality care to this group of patients (Desroches et al., 2019; Wilson et al., 2019); this suggests that more in-depth knowledge about how to best care for this vulnerable patient group is warranted.

Today, the health and social care in developed countries has been experiencing a noteworthy increase in the number of people with IDD because they are living longer and growing older. People with IDD are also at increased risk of co- or multimorbidities compared with the general population (Coughlan et al., 2020). This group has specific health needs that, to a significant extent, are modifiable and, at times, avoidable (cf. Truesdale & Brown, 2017). Here, IDD are defined as 'a group of developmental conditions characterised by significant impairment of cognitive functions, which are associated with limitations of learning, adaptive behaviour and skills' (Salvador-Carulla et al., 2011, p.175). People with IDD often have poorer health because of their lifestyle as many of them get little

What is already known about the topic?

- Mainstream healthcare is not designed to meet the healthcare needs of patients with intellectual and developmental disability.
- Registered nurses are not comfortable delivering care to patients with intellectual and developmental disability.

What this paper adds

- The registered nurses working in home care perceived that the context and organisation of care hindered the delivery of care to patients with intellectual and developmental disability.
- The nursing profession needs to engage in an open debate regarding the rights of patients with intellectual and developmental disability.
- A broad base of evidence on what actually works best in clinical practice for this group of patients, particularly in the home-care context, is still needed.

exercise, have poor diets and are overweight or obese (Coughlan et al., 2020). These individuals experience the same range of health problems as the wider population, but the pattern of illnesses they experience may be different (Kinnear et al., 2018). In addition, Heslop et al. (2014) reported that problems with coordination within and between services contributed to premature deaths among patients with IDD in the United Kingdom; in line with this, Trollor et al. (2017) reported that adults with IDD experienced premature mortality and were over-represented among avoidable deaths in Australia. It is probable that this patient group in general presents with complex health support needs when acquiring health services. How well RNs are taught and prepared to care for this group during their education is not well described. However, a recent national audit of 31 Australian universities' nursing curriculum content (Trollor et al., 2016) uncovered substantial variability in essential IDD content, with numerous gaps evident. These findings were corroborated in a Tasmania and New South Wales university setting (Furst & Salvador-Carulla, 2019). How these findings are reflected in Swedish nursing curriculum content has not yet been established.

Some studies have argued that mainstream healthcare approaches are not always designed to meet the health needs of patients with IDD (Lewis et al., 2016; Whittle et al., 2017). Disparities and inequalities in healthcare place patients with IDD at a high risk for morbidity and premature mortality (Heslop et al., 2014; Trollor et al., 2017). Therefore, responding to the health inequalities faced by them is a critically important issue for healthcare services and for RNs. The inequalities that people with IDD face start early in life and result, to an extent, from the barriers they encounter in accessing timely, appropriate and effective healthcare (Degerlund Maldi et al., 2019; Truesdale & Brown, 2017). It is reasonable to suggest that these disparities also may be due to the inadequate

education and practice of health practitioners' when caring for this patient group. Therefore, addressing the lack of knowledge about patients with IDD must be made an educational and professional priority, particularly within nursing. Furthermore, people with IDD have moved out from institutions and into the community. This shift has had consequences for them, for the role of nursing and for the delivery of care. A recent cross-sectional study found that Australian RNs had a variety of roles and engaged in a considerable range of practices related to the needs of patients with IDD (Wilson et al., 2020). Rather than the delivery of care in institutional settings, in many countries, community care has now been designated as the main provider of healthcare to patients with IDD. Thus, RNs based in community care teams are often this group's first contact point with services. Much of the care for patients with IDD is nowadays described as taking place at home (Jaques et al., 2018). Therefore, knowledge of how care delivered in the home-care setting can be perceived by RNs is imperative. Such knowledge is critical not only for the development of an evidence-based care but also in supporting RNs to work against the health inequalities present in this group of patients.

1.1 | Aim

This study aimed to explore and describe Swedish RNs' perceptions of caring for patients with IDD in a home-care setting.

2 | METHODS

This study has a qualitative descriptive interpretive design (Sandelowski, 2000). Data were collected through interviews (Polit & Beck, 2017) and analysed using a qualitative content analysis (Elo & Kyngäs, 2008). The reporting of this study adheres to consolidated criteria for reporting qualitative (COREQ) research (Tong et al., 2007).

2.1 | Study setting and context

Lakeman (2013) highlighted the importance of offering a rich description of the general context in which research has been conducted. Only then can a global audience understand the practice. In Sweden, the care of patients with IDD is primarily a public responsibility and mainly financed through taxes. County councils are the regional providers of healthcare, while the boroughs are responsible for the support services of patients with IDD residing in assisted-living facilities (Swedish Code of Statutes, 1993:387), and for patients in independent living situations (Swedish Code of Statutes, 2001:453). Care is guided by RNs (Swedish Code of Statutes, 2017:30) and support is delivered by social and support pedagogues, support assistants and enrolled nurses (support staff). Patients with IDD, regardless of the severity of their diagnosis, reside in their own apartments. Support

staff are on duty around the clock, as are the RNs, who are on call both for elective and acute care responses. RNs are responsible for several services while situated apart from the patients' living premises.

The training of RNs in Sweden is government funded. With the main subjects caring and nursing science, nursing is a 3-year university degree programme comprising generic clinical and theoretical modules. Since 2007, the degree programme has led to a bachelor's degree in nursing science and to a vocational degree in general RN. Reviewing the literature implies a lack of research on what IDD content is taught in Swedish university nursing curricula, regardless of whether it is undergraduate or postgraduate curricula; hence, RNs' preparedness to deliver relevant care to patients with IDD is not well-known.

2.2 | Recruitment and participants

Eligible participants were RNs caring for patients with IDD. The RNs were working, either in a dayshift or nightshift, in the home-care context; the RNs were either in one larger city or in one of four surrounding municipalities in Southern Sweden. A multistage sampling technique (Battaglia, 2008) was used; here, sampling was done sequentially across hierarchical levels. The first author (MA) contacted the department managers within health and social care—in addition to the disability departments—via an email containing information about the study. The department managers forwarded the information to the frontline managers, who then forwarded the contact information to the RNs in their organisation. Initially, 23 RNs expressed an interest and 22 were interviewed. The remaining RN found it difficult to arrange a time to meet, and two interviews were excluded because of poor recording quality, leaving 20 interviews ($n = 17$ women; $n = 3$ men) included in the dataset. All the participants gave their oral and written consent. The participants' mean age was 46.8 years, and they had 15 years (mean) of clinical experience and about 5.6 years (mean) of working in the field of IDD. Seven participants held a specialist education but not in the field of IDD. The remaining RNs held a generalist education (Table 1). Twelve only delivered care to patients with IDD. The remaining eight RNs delivered care to a wide range of home-care patients, including patients with IDD.

2.3 | Data collection

Given the aim, individual face-to-face interviews (Polit & Beck, 2017) were conducted in the participants' native language: Swedish. The first author conducted all the interviews, which were carried out in a clinical setting ($n = 19$) and at the university ($n = 1$). Data were collected between September 2018 and May 2019. To support reflections and in-depth narratives, a one-page written nursing case based on the findings from a meta-synthesis published by the authors (Appelgren et al., 2018) was presented

TABLE 1 Characteristics of the informants

Participant ID	Age	Clinical experience as RN (years)	Clinical experience caring for patients with IDD (years)	Education	Home healthcare setting
1	35	3	6 months	General RN	Assisted living
2	63	16	4	General RN	Assisted living
3	35	8.5	2.5	RN, specialised in district nursing	Assisted living
4	45	20	10	RN, specialised in psychiatric nursing	Assisted living
5	59	18	9 months	General RN	Assisted and ordinary living
6	33	4.5	1.5	General RN	Assisted and ordinary living
7	54	14.5	14.5	RN, specialised in district nursing	Assisted living
8	43	3.5	2	General RN	Assisted living
9	54	18	8	General RN	Assisted living
10	39	4	3	General RN	Assisted living
11	61	40	7	RN, specialised in district- and psychiatric nursing	Assisted living
12	37	10.5	3	General RN	Assisted living
13	54	32	16	General RN	Assisted and ordinary living
14	51	20	7	RN, specialised in ambulance nursing	Assisted living
15	39	12	3, 5	RN, specialised in ambulance nursing	Assisted and ordinary living
16	44	15	15	RN, specialised in district nursing	Assisted and ordinary living
17	41	5	3	General RN	Assisted and ordinary living
18	47	15.5	2.5	General RN	Assisted and ordinary living
19	52	13	2	General RN	Assisted and ordinary living
20	50	16	4	General RN	Assisted living

to the participants before the interviews began. The relevance of the case had been piloted with two RNs outside our sample; the pilot resulted in no modifications. All interviews began with the open-ended overarching question, 'How do you as an RN perceive caring for this group of patients?', followed by general probing (Polit & Beck, 2017) questions such as, 'What do you mean?', 'Can you please give me an example?' and 'Can you tell me more?'. The interviews lasted between 30 and 80 min and were recorded and transcribed verbatim.

2.4 | Data analysis

The transcribed text was subjected to a qualitative content analysis (Elo & Kyngäs, 2008). Texts were read repeatedly to grasp the whole meaning and to make sense of the data (i.e., a naïve reading).

This process included open coding, where notes and tentative understandings were written in the margins while reading the text. Meaning units, a sentence or several sentences of the text conveying the meaning of the phenomenon in *foci*, were extracted into condensed meaning units. The meaning units were then labelled with codes. The codes were compared and brought together in terms of their similarities and differences to formulate subcategories and categories. All authors participated in the continual process of iteration by focusing on the whole and the parts; this was done to check and confirm the interpretations, that is, investigator triangulation (Denzin, 2006). Intercoder agreement (Neuman, 2000) was also applied to verify the process of interpretation until the categories emerging from the data were found to be mutually exclusive. Table 2 is an excerpt that gives an example of the analysis process. To enhance the analysis' rigour, all quotes were translated from Swedish to English by a certified English editor experienced within the field of

TABLE 2 Example of process of analysis

Meaning unit	Condensed code	Code	Subcategory	Category
<p>“And even if I do not have plenty of time (laughter), I somehow take the time needed. I don’t want to give the impression that I’m stressed or that I have to attend to the next patient. Therefore, I’m calm ... that’s the impression I want to give: ‘I’m here right now. This moment is for you and me and what I’m about to do here.’” (RN 2)</p>	<p>Even if I do not have plenty of time, I somehow take the time needed. I don’t want to give the impression that I’m stressed. Therefore, I’m calm ... that’s the impression I want to give: ‘I’m here right now. This moment is for you.’</p>	<p>Even if I do not have plenty of time, I take the time needed. I want to give the impression of calm ... This moment is for the patient.</p>	<p>Managing time</p>	<p>Nursing held hostage in the context of care</p>
<p>“Now afterwards, one can think, as you mentioned, the Act Concerning Support and Service for People with Certain Functional Impairments has existed for 25 years and to what extent does one engage in the act in nursing education? For example, it’s... well, I don’t recall anything.” (RN 14)</p>	<p>And now afterwards, one can think, the Act Concerning Support and Service for People with Certain Functional Impairments has existed for 25 years and to what extent does one engage in the act in nursing education? Well, I don’t recall anything.</p>	<p>The Act Concerning Support and Service for People with Certain Functional Impairments is 25 years old, but not mentioned in nursing education.</p>	<p>Not supported with adequate knowledge in education</p>	<p>Care dependent on intuition and proven experience</p>
<p>“This group is also disadvantaged. Not many people are interested in it.” (RN 4)</p>	<p>This group is also disadvantaged. Not many people are interested in it.</p>	<p>Disadvantaged group, no one is interested in it.</p>	<p>Invisible patient group</p>	<p>Contending for the patients’ right to adequate care</p>

health service research. The translations were then checked by the authors to ensure accuracy and understanding.

3 | ETHICAL CONSIDERATIONS

The current study was performed in compliance with the ethical guidelines of the Declaration of Helsinki (World Medical Association, 2013) and was approved by the Regional Ethical Review Board in Lund (2018/472). The data were stored in accordance with the General Data Protection Regulation (GDPR) (EU, 2016).

4 | FINDINGS

Our analysis indicated that RNs' perceptions of caring for patients with IDD in a home-care setting can be understood from three overarching categories: *nursing held hostage in the context of care*, *care dependent on intuition and proven experience* and *contending for the patients' right to adequate care* (Table 2). In this section, the categories are exemplified by quotations (Q) (Boxes 1–3).

4.1 | Nursing held hostage in the context of care

The category *nursing held hostage in the context of care* was interpreted as reflecting the RNs' perceptions of how their work is organised and how this could impact the care they want to deliver. It was clear that the structure of their everyday work was perceived as including several challenging aspects. One such challenge was being responsible for many different services, which led to a heavy workload with a high number of patients to attend to. This meant that the RNs were not able to visit the services they were responsible for on a regular basis. Instead, they perceived themselves as mainly engaging in fragmented troubleshooting, with a maximum of 10 min per patient. Despite RNs perceiving they had a lack of time and having far too many patients to care for, it was important for the RNs to project calmness to their patients. The RNs perceived that the context of care resulted in inefficient and incomplete work and that most of their time was spent putting out 'spot fires' (Box 1, Q1). The RNs described that continuity, trust and long-term relationships were vital for the care of this patient group, but the present work structure was perceived as counteracting their attempts to foster these relationships. Without quality relationships, the RNs disclosed that it would be impossible to conduct closer check-ups or examinations of the patients. A long-term relationship was considered a prerequisite for RNs to be able to interpret and understand their patients (Box 1, Q2).

As a result of not being present at the different services on a regular basis, most of the RNs felt overly reliant on the support staff's descriptions of and information about the patients. Vital information for the RNs included how to communicate with the patients; their habits, likes and dislikes; and changes in the patients' behaviour, health and well-being. This presented challenges in how to act, plan

Box 1 The category–Nursing held hostage in the context of care

"...and we have talked about it, that we want, but how do we find the time?... everyone runs like scalded rats and have their own business to attend but... therefor there is no time for these finesses that had improved the care. Or, it's not finesses, it should be part of the care... that you're working in team, but there is not time and it's the same for primary care and the hospitals, I'm sure it's not because of malice, it's just lack of time... try to convey or share what you've discovered or what was decided, but you have to rush to next patient and you have forgotten about the former. And it's almost as work and work on something and things happens but it's not conveyed to the others so... somehow it's almost as it's undone... it's... fire extinction." (Q1, RN8)

"I had one patient and it took two years before he even opened the door, I was to dress a wound at his finger, then the finger came out through the door. I showed my face, I said hallo every time but he said nothing. After two years he said hallo to me for the first time. It is absolutely after their, that is one cannot just barge in. One cannot barge in one has simply take the time they need to get to know one." (Q2, RN20)

"But they, the support staff knows the patients better than what we do so, unfortunately, we do separate, isolated measures when we work. We maybe meet the patients, some of them ten minutes a week. We cannot see, that is patterns in their life's, habits or if something is crazy or wrong or so on..." (Q3, RN1)

"Or when the support assistants who work close to the patient and we don't speak the same language, we look at the problems in different ways, and you are supposed to meet in order to help the patient, or the patient is in pain, support assistants don't look at it the same way either." (Q4, RN4)

"Most of our patients got a very good network... in comparison with somatic patients... they have a team surrounding them in a whole different way, they have their physician, the have physiotherapists and occupational therapists who are involved... to me, that is very positive." (Q5, RN10)

and evaluate care correctly (Box 1, Q3). Another challenge described by the RNs was when they perceived that the support staff did not possess the adequate knowledge in care or the ability to express themselves in a way the RNs could understand when being contacted about a patient's problems. The RNs described that this was because of different types of education, which also meant different regulations, language and terms and different perspectives, for example, pedagogic versus nursing care perspectives regarding patients in general (Box 1, Q4).

Despite some challenges, occasionally being subjected to support staff was not always perceived as an issue by the RNs; for example, when the patient and RN were unfamiliar with each other, the presence of the support staff resulted in the patient feeling safe and secure. This supported the RNs' efforts in care. The RNs described this, along with interprofessional collaborations, as necessary and beneficial for the patient's care. It was also a way for them to view

the care delivery as less fragmented, making use of existing knowledge and experiences with other professionals working around the patient (Box 1, Q5).

4.2 | Care dependent on intuition and proven experience

The category *care dependent on intuition and proven experience* was interpreted as reflecting the RNs' perceptions of existing knowledge or, rather, the lack of knowledge among themselves and the other healthcare professionals working with the patients. The RNs stressed their lack of adequate knowledge in pre-registration education about IDD (Box 2, Q1). They perceived that they had to manage care on their own, working without evidence-based knowledge and simply hoping that the strategies they applied in care would work out for the best (Box 2, Q2). Furthermore, the RNs critically reflected on the fact that there is no specialisation for RNs concerning IDD, although specialisations are found within many other fields (e.g. psychiatry, intensive care and anaesthesia). The RNs suggested that a specialisation is needed, particularly because caring for those with IDD is perceived as highly complex (Box 2, Q3).

Here, the need for a deeper kind of knowledge that could go beyond theoretical knowledge is also reflected on. Although the RNs requested more knowledge about IDD, they also perceived that even this was not always sufficient. Sometimes, the RNs needed to go beyond this type of knowledge through intuitive awareness and proven experience. This could mean intuitively knowing what lines not to cross when caring for their patients. The RNs stated that they also needed practice situations to develop such intuitive awareness (Box 2, Q4). It was sometimes perceived as hard for the RNs when trying to reach out while at the same time not intruding. Sometimes, RNs who all wished to do good could not do anything because the patient was not open to receiving care. Furthermore, the RNs had to use their creativity and adapt and adjust to the patients to deliver care. Caring for patients with IDD was perceived as always needing to be on the patient's terms. Here, one way of reaching the patient could be through their hobbies or interests. By reaching out from these perspectives, RNs could gain the trust of the patients (Box 2, Q5).

Communicating with patients with IDD, of whom many are without a verbal language, was described as a big challenge for the RNs, who often perceived that they lacked the necessary knowledge for how best to communicate with their patients. The RNs raised concerns about not knowing how the patient felt about the care delivered and not knowing how the patient wanted the care to be delivered. In addition, they lacked the time to find out, resulting in the fear that they would almost abuse the patient (Box 2, Q6). Sometimes, very simple methods could facilitate care. For example, this could be done by preparing the patient by repeating information 3 to 4 days in advance and showing pictures or videos. The RNs could also use the same objects all the time, such

Box 2 The category—Care dependent on intuition and proven experiences

"It doesn't matter if we are occupational therapists, social pedagogues or enrolled nurses or whatever... we can never get enough of knowledge... for these patients. But many times, you have to manage of your own... and do as best you can, because where do we find it? Where do we find that knowledge or that education is my question?" (Q1, RN2)

"Instead, one has had to learn from one's mistake, one has trampled on mines. If I don't hear anything negative then my concept is working well." (Q2, RN15)

"In my opinion, and with regards that we have implement an IDD-nurse, and there is a huge amount of RN specialisation educations, operation theatre nurse, well, you name it, a huge amount... therefore it ought to be a specialist education specific within IDD nursing and related problems. Yes, one can have psychiatric diseases but so can every one without IDD. Therefore, I think it is a broad specialist education [psychiatric nurse], it ought to be an education specific about IDD. Because as I stated before, they get older. They all get older and shall receive home care, hence it requires a specialist education. Look at the newly implemented psychiatric ambulance. It's very complex for ambulance nurses and firemen to meet these patients. And I've heard that it's going very well. Even there it's about meeting them in a proper way, on their terms. We aren't there yet. I haven't been after four years of university studies." (Q3, RN15)

"I don't know how much of that you can learn in school. It rather needs more of practice to be able to learn, because you need to be with people with IDD to be able to understand people with IDD." (Q4, RN6)

"One thing of importance, is that many has hobbies, if you then read upon, you don't need to read much at all, I was going to read up on football and said to a patient today your team is playing. Heaven on earth he has never talked that much before. Many patients are very fond of animals and I tell them about my dog, 'do you want to see a picture of him? You can't enter and say: you had a stomach problem. You always need to sense oneself.... They [support staff] call us magicians, one has to adapt and accommodate to the patient..." (Q5, RN20)

"Often when we are about to communicate with the patient... it becomes through the support assistants who are working with the patient... so they actually become the patient's voice, we listen to them almost more than the patient himself... so it's very important what they tell us, what they express and what they know, because we are forced to listen to the patients' voice through them." (Q6, RN1)

"You don't have the knowledge of how to do... and what's important. For example, pictures, it became so apparent when Helen [the community IDD-nurse] were about to send a patient for examination... "ah, that's what I should have done, and so I thought of all the times I should have done like that... but it never crossed my mind." (Q7, RN 18)

"I know they exist (communicative tools), but I never use them." (Q8, RN19)

as the same needle box and nameplate, to facilitate patient associations, but in most cases, this was not common knowledge for the RNs (Box 2, Q7). Sometimes, the RNs knew that augmentative

and alternative communication existed, but they did not use these methods (Box 2, Q8).

4.3 | Contending for the patients' right to adequate care

The category *contending for the patients' right to adequate care* was interpreted as reflecting the RNs' understanding of the constant need to act as the patient's defender as a part of the care process. The RNs noted that patients with IDD were not given a voice of their own (Box 3, Q1), were treated like small children and were often paternalised (Box 3, Q2). The RNs described that when the patients contacted their primary caregivers, they were often not listened to or not taken seriously. However, when the RNs contacted the primary caregivers on behalf of the patients, they were mainly listened to, except when it came to psychiatric care. Here, the RNs described that it was as if no one wanted to take responsibility for this group

of patients when they suffered from additional psychiatric disorders. If it was hard to obtain adequate healthcare for patients with IDD, it was twice as hard for those who also had a psychiatric disorder. Psychiatric problems were perceived as not being taken as seriously as physical problems, and as a result, the patients were not offered adequate psychiatric care (Box 3, Q3).

The RNs further described that the patients not being acknowledged with a voice of their own led the patients with IDD to become an invisible group. Not many were interested in working in this context, which made it difficult to recruit healthcare professionals (Box 3, Q4). The RNs reflected on whether this could be because of societal rules in general, as in being told not to stare at people with IDD, and, as a result, ignoring them (Box 3, Q5). This category reflected that the RNs perceived challenges in delivering and receiving adequate and quality healthcare for patients with IDD compared with patients without IDD. The RNs described that the attitudes among healthcare professionals and in society strongly affected the care patients with IDD received. They pointed out that the elderly in

Box 3 The category—Contending for the patients' right to adequate care

"There are many who not speak up for our patient group, one speaks a lot about them, a lot about how it should be but one is not speaking up for them." (Q1, RN4)

"I think the worst are those thinking that these patients are cute. Who enters the living of 45-year-old women and treats her as a child because of her intellectual disability making her look younger than her age? I think that this influence care a lot. The paternalization of patients with IDD. So, it is not a negative stereotype but it is a problematic stereotype" (Q2, RN6).

"I mean that this is a patient group that definitely not are receiving what it should receive, and it is not respected, that psychiatric problems don't seem to be on par or prioritised as somatic problems, then it is beat the big drum and this should be fixed and done. But psychiatric problems they are allowed to go on. They are not taken seriously; it is not so important and not acute in a way but it is even more acute. Then that someone need to go around feeling unwell day in and day out that is really weird. You would never behave like that to a person with cancer. No, we have to deal with it when we find the time. Then what both cases can end up in is a case of death if it develops towards being suicidal." (Q3, RN8).

"When I started [working with this group of patients], there were physicians at the habilitation and they had a huge and solid knowledge... that's hard today, I don't have... I have the same physician at the moment but it has been extremely many physicians and no one have any interested in this... patient group. Today it's a lot of psychiatry also... within this patient group. But there is no interest." (Q4, RN11)

"It's something old since growing up, my mom and dad said "never laugh at them and never stare at them", then I thought like "ok, I rather look away". (5, RN15)

"I work a lot with elderly people... and there it is... eldercare... and one get the feeling... and there they haven't got educated enrolled nurses as they would have in a nursing home for elderly people... and they haven't... I work within my context and they work within their context... and they live within IDD setting. But if they didn't have an IDD diagnosis, well they would probably live in their own home, but be able to come to a nursing home where there are other competencies than at IDD settings when it comes to basic nursing care and where one is enrolled nurses rather than pedagogues, as many of them are in IDD settings. It's like one haven't kept up with time. Patients with IDD... they had not counted on that they also would get old." (Q 6, RN12)

"I say that I'm so fed up with the fact that they are getting second class care. But that's why we are here, we fight and make fuss. We fight and make fuss for them. That's the way it is, that you often, like when I started to notice... I've been fighting for a guy, an older gentleman who I suspected started to become demented, for many years ago. They didn't want to do an x-ray, they didn't want to examine him, "how is he supposed to participate?" and I thought "that's your problem to solve". So, they never investigated it and gave him the diagnose "dementia-like symptoms". (Q7, RN20)

"You have to start with the patient, what he or she wants, and then, somehow, put it in the perspective of what is reasonable. If the patient decline and says "I don't want to do this examination"... then one have to think "is this examination life changing?"... and then you have to ask yourself "have the patient received... have she or he understood the information given?... of the need of the examination. And if the patient have understood and taken an active decision, he or she is aware of this... than I think you have to settle with that, because sometimes I feel that the old culture of institutionalisation still remains... that we decides and we know what's best for you. But ourselves, we say "no thank you", I mean, if I don't want to go to the dentist I cancel. I decide myself which treatments I want to undergo and what drugs I put in to my mouth". (Q 8, RN 14)

"But at the same time, I think it is important that even if you have to work in a slightly different way, it is probably still important that they do not feel that they are treated in a special way. Because I think they feel enough different anyway". (Q9, RN 16)

particular needed to be offered nursing competence in the form of care rather than pedagogical competence. The RNs implied that the context of care had not kept up with developments in society or the statistics reflecting that this group of patients are reaching a much higher age than ever before (Box 3, Q6). Hence, the perceptions of a knowledge gap about ageing and dementia were present. The RNs furthermore stressed that there were disparities and inequalities present in care, meaning that the RNs perceived themselves as fighting for the patients' right to the same care as others (Box 3, Q7).

In the category *contending for the patients' right to adequate care*, the RNs' strong sense of the patients' rights concerning freedom and autonomy were also mirrored. Even if examining the patient was often perceived as demanding because of communication difficulties, the RNs nevertheless felt that the care had to originate from the patient's perspective and be what the patient wanted before being framed in the perspective of what seems reasonable. If the patient did not want to take part in examinations and treatments, they had the right to say no, given that the patient understood the situation (Box 3, Q8). However, this approach was not always the case. RNs described an awareness that paternalism still played a large role in the culture within the field. There was also an awareness that the patients both felt alienated and different from their peers without IDD. Hence, the RNs described that it was vital to avoid singling them out by treating them too differently (Box 3, Q9).

5 | DISCUSSION

This study aimed to explore and describe Swedish RNs' perceptions of caring for patients with IDD in a home-care setting. The most pertinent findings within the overarching categories—*nursing held hostage in the context of care*, *care dependent on intuition and proven experience* and *contending for the patients' right to adequate care*—will be discussed.

Our findings represented by the category *nursing held hostage in the context of care* reflected how the organisation of the RNs' work did not favour or support the care that the RNs wanted to deliver to this group of patients. The RNs held the view that they were designated and responsible for too many services, resulting in the daily delivery of fragmented and troubleshooting care. The RNs perceived they were constantly putting out 'spot fires', and this did not fall in line with the best practice in community-based nursing care, which is meant to be continuous and not acute (Meleis, 2017). Hahn and Fox (2016) found that community RNs are challenged in the coordination of fragmented healthcare, which requires multiple phone calls and emails to access the resources needed. Furthermore, in their study of chronically ill patients, Frandsen et al. (2015) found that greater fragmentation of care delivery was consistently associated with worse care quality and higher costs. One way to counteract fragmented care delivery and acknowledge and deal with the complexities associated with patients with IDD could be by implementing specialist IDD RNs to plan and coordinate these patients' care. Our findings also show that working in interprofessional teams was perceived as

partially counteracting fragmented care delivery. This is supported by others who found that interprofessional collaborations in this patient group can counteract unmet care needs and improve health outcomes (McNeil et al., 2018). Despite the challenges in the context of care, the RNs in our study managed to cope with their perceptions of a constant lack of time in care. It stood out as important for the RNs to appear calm and take the time needed in care when meeting with the patients. This is corroborated by Ndengeyingoma and Ruel (2016), who found that it was vital to let the patients with IDD set the pace for care. Otherwise, it was not possible for the RNs to deliver adequate care. Therefore, making reasonable adjustments to the RNs' care delivery and their role seems as a necessary step in the Swedish home-care context.

Our findings also mirrored that the care for the patients in this context was mainly based on a method of trial and error, as reflected in the category *care dependent on intuition and proven experience*. The RNs perceived a lack of clinical skills training about IDD in pre-registration education. This lack of education applied to both the RNs and the rest of the team working with these patients. Research has shown that RNs educated about IDD are improving the care delivery for this group of patients through teamwork and the incorporation of specialist knowledge and research, which are factors known to support improved quality of care, an evidence-based practice and the delivery of safe effective care across varied settings (Desroches et al., 2019; Doody et al., 2019; Wilson, Wiese, et al., 2019). Ever since the closure of IDD institutions in the 1960s, RNs have been caring for these patients in diverse healthcare settings (Jaques et al., 2018). Although the RNs highlighted the urgent need for education and an expanded knowledge about IDD, intuitive awareness and their nursing intuition were also described as important in care. Green (2012) proposed that nursing intuition is a type of practical intuition and, thus, a valid form of knowledge that should be acknowledged and recognised in the provision of care. However, it also seems reasonable to acknowledge the importance of offering care based on the best available evidence-based knowledge. The latter stood out as not being the case in relation to RNs' ability and skills concerning communication as a part of the care for those patients without verbal forms of communication. Fortright and sincere descriptions were reflected in which the RNs confessed to being aware of augmentative and alternative communication (AAC) that would facilitate the care of this patient group. Despite this, none of them had learned how to implement AAC as a part of their care. Instead, they relied on the interpretations of support staff. Our findings are corroborated by Vestin et al. (2018), who found that 84.7% of the Swedish healthcare professionals rated their AAC knowledge as low. Other researchers have found that it is possible to achieve equal health outcomes if reasonable and achievable adjustments are in place in the care of this patient group (MacArthur et al., 2015). Being able to interact and communicate is the cornerstone of building a respectful and long-term nurse-patient relationship, and it is also crucial in being able to assess, implement and evaluate the care needed for this group of patients. Our findings imply an overall urgency in that the RNs' needs for

professional development within the field of IDD should be made known to their employers, the municipalities. In particular, their need for in-depth knowledge and skills regarding communication and communicative tools appears to be an especially important educational starting point.

Our findings, as evident in the category *contending for the patient's rights to adequate care* reflected how the care for this group of patients meant being vocal about the issue and fighting for the patient's right to receive the right care at the right time and by the right person on a daily basis. This was particularly obvious when it came to the provision of psychiatric care, in which case the RNs could yell and fight for the patients without result. Research has implied that there are barriers, both on a systematic and personal level, to accessing the relevant psychiatric care for patients with IDD, for example, having IDD meant that the patients did not meet the service criteria for psychiatric care (Whittle et al., 2017). Indeed, patient advocacy is central for the nursing profession and has a historical foundation to ensure health equity and social justice for both individuals and society at large (ICN, 2012). However, our findings reflect a need for advocacy that extends beyond what should be expected in a modern healthcare context. Nevertheless, it is important to acknowledge that the RN is significant in the provision of advocacy (Hughes, 2009) and is vital in ensuring access to appropriate services for this group of patients (Devine & Taggart, 2008; Encinares & Golea, 2005). Brown (2016) stated that considering these patients' history of marginalisation in society, it is particularly important for RNs to function as advocates with and on behalf of patients with IDD to improve health access and outcomes. According to the United Nations Convention on the Rights of Persons with Disabilities (2006), people with disabilities have the right to the highest attainable standard of healthcare. Yet there are reports of patients with IDD who have faced disparities and inequalities in care, even dying from preventable causes (Heslop et al., 2014; Hosking et al., 2016; Trollor et al., 2017). Our findings also reflected the RNs' view that these patients are being marginalised and are considered invisible. It is important to acknowledge that this group of patients say they no longer want to be disregarded but instead want to take their place in the world and play a larger role in society (Manthorpe et al., 2003). Therefore, RNs are important in challenging the stigmatisation this group experiences (Braveman et al., 2017) and for contributing to eliminating the inequities in health outcomes among these patients.

6 | STRENGTHS AND LIMITATIONS

The results of our study have been evaluated in terms of their trustworthiness (Lincoln & Guba, 1985). The study setting and context have been described as being able to facilitate an understanding (Lakeman, 2013) of our findings. The informants varied in gender, age, education and work experience, which should be regarded as sufficient to ensure variations in perceiving the same phenomena. However, the heterogeneity regarding gender ($n = 17$

women; $n = 3$ men) may be a concern; still, this is considered typical for the Swedish nursing workforce, regardless of context, because only about 11% of RNs are men (Statistics Sweden, 2018). Together with the informants' heterogeneous characteristics, this may support the transferability of our findings to comparable contexts. To ensure the study's rigour, all the authors worked together throughout the analysis. Interpretations and categorisations were verified both by investigator triangulation (Denzin, 2006) and by intercoder agreement (Neuman, 2000) to ensure that the findings would represent the most credible understanding of the texts. This would enhance the confirmability and trustworthiness of the present study.

7 | CONCLUSION

The present healthcare context for this group of patients stood out as too fragmented to meet the needs of these patients because the RNs in the current study perceived that they could not deliver the care they wanted to. Avenues to make reasonable adjustments to the RNs' care delivery and their role should become an option in standard practice in the home-care context. Considering the overall lack of understanding about this patient group and IDD, in general, and the consequences for care, it may be beneficial to explore the potential advantages of a specialist IDD RN role and the implications this may have on improving care and its outcomes for patients with IDD within a Swedish context. The profession needs to engage in an open debate regarding the rights of people with IDD. Particularly, as the RNs felt a need to fight for these patients' rights as a part of their care on a daily basis. The RN's role in care should also be a part of this discussion. This could support this patient group in gaining access to specialist support, such as psychiatry or other forms of care, when needed. However, it could also support the unravelling of the issue, which is that this group of patients does not seem to receive equal and safe care compared with other patients. What still seems to be absent is a broad base of evidence within nursing on what actually works best for this group of patients in the home-care context.

Finally, our findings have implications for research, education and practice. For example, Sweden would benefit immensely from following the more recent Australian initiatives within the field of nursing and IDD, that is, by conducting a national mapping study of the educational opportunities within the field of IDD (Furst & Salvador-Carulla, 2019; Trollor et al., 2016) and performing a national survey (Wilson et al., 2020) to explore how many RNs work in services caring for people with IDD, in what settings they work and their roles in care. As with many other countries, Sweden has a national register for newly qualified nurses; however, how many of those going on to work within the field of IDD are unknown. Information regarding this is urgent because it is needed to underpin and guide any further research into nursing and the field of IDD. It is also crucial for informing higher educational institutions (HEIs)

about what skills, competences and knowledge actually need to be integrated and taught in the national nursing programmes curricula. A recent Australian study suggested that content regarding how to communicate and support people with IDD well-being and health is critical (Wilson et al., 2019). We anticipate that the last 5 years of increased international attention into research in nursing and IDD will support a raised awareness in the nursing community about this patient group, their need for fair and equal quality care and the skills and competences that are needed as an RN to offer and deliver such care.

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CONFLICTS OF INTEREST

The authors declare that they have no competing interest.

AUTHORS' CONTRIBUTIONS

MA and GB were mainly responsible for the study inception and design while receiving important intellectual contributions from KP and CB. MA was responsible for the data acquisition and for drafting the initial manuscript. MA performed the interviews. MA, KP, CB and GB performed the data extraction and analysis. KP, CB and GB were additionally responsible for critical revision of the paper and for adding important intellectual content. GB, KP and CB supervised the study. All authors read and approved the final manuscript.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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