

RESEARCH ARTICLE

Collaboration and guidelines for the coordination of health care for frail older persons with intellectual disability: A national survey of nurses working in municipal care

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Abstract

Aims: To describe and compare perceptions of collaboration between care providers on the part of three groups of Registered Nurses working in municipal care and having particular responsibility concerning the care of frail older people with intellectual disability (ID); and, furthermore, to investigate the presence of and compliance with guidelines for the coordination of care.

Design: National survey study with cross-sectional design.

Methods: Nurses ($N = 110$) with key positions concerning people with ID answered a national questionnaire about collaboration, guidelines and coordinated individual plans. Descriptive and comparative statistical analyses were applied.

Results: The meetings on cooperation and coordination of interventions were attended most frequently by nurses, and least frequently by social workers. The nurses were overall satisfied with the collaboration but perceived shortcomings in the case of inpatient and outpatient psychiatric care. Only in about half of the meetings for making care plans participated the people with intellectual disability and next of kin.

KEYWORDS

care plan, collaboration, community nursing, disability, integrated care, older patients, patient participation, questionnaire, specialist nursing, survey

1 | INTRODUCTION

Many older people need both care at home provided by the municipality and care at hospital for periods and then continued help in outpatient care, because of multimorbidity (Bähler et al., 2015). However, the healthcare systems have mainly been developed for specific diseases rather than to meet the needs of people with multimorbidity. Using different services to treat each disease may become duplicative and inefficient, and burdensome and unsafe for patients

because of poor coordination and integration of interventions (Reed et al., 2005). Focusing on a more coordinated and integrated care provision is an international policy issue, and improvement is ongoing worldwide (Delnoij et al., 2002; Reed et al., 2005; WHO, 2016). However, there is no universally established term for designating this type of care; different terms are used in different disciplines. The most commonly used term “integrated care” is used synonymously with “coordinated care” or “seamless care” to indicate a contrast to fragmentation in care (Jansen et al., 2006; Read et al., 2005).

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Lifelong intellectual disability (ID) is characterized by onsets occurring before the age of 18 and by statistically significant limitations in intellectual and cognitive functioning, thus limiting the person's ability to learn and reason, affecting decision-making and problem-solving. The reduced ability for adaptive behaviour implies a lack of skills necessary for day-to-day living such as being able to communicate effectively, interact with others and take care of oneself (American Association on Intellectual & Developmental Disability, 2020). Thus, older people with ID constitute a specific group having a comprehensive need of both social services and health care from different care providers, for which reason they are highly dependent on effective coordinated care. Better coordination of care could reduce unnecessary hospitalization, fragmentation and discontinuity for frail people with ID and with multiple chronic conditions (Farrington et al., 2015).

2 | BACKGROUND

People with ID are among the most frail groups in society, having a reduced ability to understand new and complex information and with a large burden of diseases in adults (Kinneer et al., 2018). The frailty caused by multimorbidity is particularly prevalent in older people (Axmon et al., 2018; Cooper et al., 2015; Hermans & Evenhuis, 2014; McCarron et al., 2013; Sandberg et al., 2017). Multimorbidity, defined as affliction with two or more chronic diseases (Johnston et al., 2019), has been found in 80% of people with ID and associated with age and severe ID (Hermans & Evenhuis, 2014). In a care situation, health problems are often expressed by such people in an atypical way, which means that there is a high risk of staff not recognizing these problems, that is diagnostic overshadowing (Cooper et al., 2015). Failure to correctly detect health problems means increased risk of incorrect treatment and negative impact on the quality of life of the person with ID. Staff should have in mind that when it comes to people with ID, multimorbidity is highly likely and requires appropriate and timely investigation and treatment. The development of guidelines for recognizing multimorbidity and health-care needs is critical when it comes to mitigating the negative impact of multiple chronic conditions and preventing additional disease burden in the case of older people with ID (McCarron et al., 2013).

Coordinated or integrated care implies an overall healthcare system with a variety of services involving different professionals and characterized by communication, cooperation, quality and efficiency (Delnoij et al., 2002; Jansen et al., 2006; Lawless et al., 2020; Petrakou, 2009; Reed et al., 2005). For decades, both patients and professionals, politicians and researchers have been calling for more coherent and better coordinated care. Sweden has over the past two decades introduced in legislative texts a demand for the coordination of health care and social service, with prominence given to shared care planning at discharge from hospital (SFS 2017:612; SFS 2017:30; SFS 2019:909). The intrinsic complexity of achieving coordination between different care providers has presented statistically significant challenges. There are cultural, administrative, financial

and competence barriers that need to be overcome when different professionals from various organizations work together (Delnoij et al., 2002). There are very few examples in practice of coordinated care pathways being used as part of care planning for people with ID (Gates, 2006). Nurses working with people with ID in the municipal framework have a crucial role to play in the coordination of care. However, reviews found a limited amount of nursing research in the literature, even in the case of countries where intellectual disability nursing is a specialty, such as the UK, Ireland, Canada and the USA (Doody et al., 2019; Griffiths et al., 2009; Jaques et al., 2018). Sweden has no such specialty, but in some municipalities, there can be a nursing post that does involve specific responsibility for the care of people with ID. These nurses may have developed unique skills in communication, advocacy and person-centred care (Jaques et al., 2018) and therefore can have perceptions of the quality of collaboration, which differ from those of other nurses with general responsibility for all citizens in a municipality. Thus, to ensure a better understanding of the implementation of coordinated care for the people with ID and therefore to enhance the quality of such care, there must be follow-up both of the collaboration between the different care providers and of the compliance with guidelines. The first aim of the present study was to describe and compare perceptions of collaboration between care providers on the part of three groups of Registered Nurses working in municipal care and having particular responsibility concerning the care of frail older people with ID. A further aim was to investigate the presence of and compliance with specific guidelines for the coordination of care for older people with ID. The aims are based on three specific research questions: (a) Do medically responsible Registered Nurses (RNs) in the municipal framework consider that the coordination of care is sufficient and works well for people with ID?; (b) When it comes to the view of collaboration and the coordination of care, are there differences between medically responsible RNs in the municipality who have a broad assignment and those who have a specific assignment for people with ID?; and (c) Do the medically responsible RNs have experience of using guidelines for coordination and cooperation between different care providers?

3 | DESIGN AND METHODS

This cross-sectional design is based on a national survey of three groups of RNs holding key positions concerning people with ID in Swedish municipal health care.

3.1 | The Swedish social service and healthcare system

3.1.1 | Social service for people with ID

People with comprehensive and long-standing disabilities are entitled to special individual support and service from the municipality,

in accordance with the Act Concerning Support and Service for People with Certain Functional Impairments (SFS 2019:883), hereinafter referred to by its Swedish acronym LSS. The Act is directed towards three groups of people with permanent disabilities, one of them being people with ID. A person with ID can also, if necessary, receive service and support in accordance with the Social Services Act (SFS 2019:909). This Act applies to everyone in the population but focuses on children, people with disabilities and older people.

3.1.2 | Health care for all

In Sweden, the responsibility for health care is shared between government, regions ($N = 21$) and municipalities ($N = 290$). The access to health care is regulated by the Health and Medical Services Act; it is based on assessments of the needs of the individual and is provided on equal terms for the entire population (SFS 2017:30). The role of the government is to establish laws, policy and guidelines and to set the political agenda for providers of health care and social service on the regional and municipal levels. The health care on the regional level is divided into primary health care and specialist health care (inpatient hospital care and outpatient specialist consultation). The responsibility of the region covers assessments leading to diagnosis, treatment and follow-up.

There is at least one RN with the position of Medically Responsible Nurse, hereinafter referred to as the MRN. The overall responsibility of the MRN is to ensure that the health care provided by the municipality is of good quality and secure for patients (National Board of Health & Welfare, 2019). Some municipalities also have an RN with special responsibility for people with ID receiving support in accordance with the LSS Act. An LSS nurse works closer to the persons with ID than does an MRN, who performs management tasks.

3.1.3 | Coordination of social service and health care

When an individual needs assistance from both principal care providers, that is the municipality and the region, a Coordinated Individual Plan (*Samordnad Individuell Plan*), hereinafter referred to as the CIP, should be drawn up. The individual's approval is needed, and he or she shall be invited to participate in care plan meetings. This model of coordination was introduced into the Social Services Act (SFS 2019:909) and the Health and Medical Services Act (SFS 2017:30) in 2010. Furthermore, in 2017 the responsibility for coordination of care was broadened to include somatic and psychiatric health care after discharge from hospital. CIP was integrated into this act (SFS 2017:612).

3.2 | Participants

The inclusion criterium was one RN from each municipality who had particular responsibility for older persons with ID. The eligible RNs

were identified through searching on the web pages of Sweden's 290 municipalities and were asked via email whether they were interested in participating in the study. Whilst some of the largest municipalities had more than one such nurse, it happened that the same nurse had the responsibility in more than one of the smallest municipalities. The number of eligible RNs came to 300. Separate emails were sent to 22 municipalities, which lacked information on their webpage about specific RNs with the responsibility in question. However, these emails went unanswered.

After three reminders, a total of 114 RNs had consented to participate in the study, but four were excluded due to missing data in the questionnaires. Thus, the study group consisted of 110 RNs, representing 39% of the municipalities (112 of 290). Sixty-seven were employed as MRNs with broad responsibility, 19 were LSS nurses with specific responsibility for the ID service, and 24 were MRNs with LSS, that is responsibility for ID service and overall responsibility.

3.3 | Questionnaire

Since no suitable measure for this study was found in the literature, a questionnaire was constructed from the perspective of the RN responsible for the health of older persons with ID. Developing such a questionnaire was considered necessary in that the goal was to perform a national survey of the core features of integrated care. The questionnaire, named "Coordination between providers of healthcare and social service for older people with ID," was developed by four researchers (GA, MP, JK and IR). This development involved several seminars and a literature review of scientific articles of health care for older people with ID. We were guided by the government directives on collaboration and coordination between different care providers for frail older people.

The questionnaire consisted of 30 items. There were nine demographic background questions, followed by 21 main questions concerning collaboration and the application of guidelines for cooperation and coordination. The main items included subquestions focusing on specific care providers. The answer alternatives differed between the items in accordance with the specific information we were looking for: yes/no or a 5-point Likert scale ranging from 1 (always/very good) –5 (never/very bad). The last question in the questionnaire was open-ended: "Do you have any further comments about collaboration?"

3.4 | Data collection

Through the university survey system, Survey & Report (Sunit, licence for Lund University), the questionnaire was sent by email to the eligible nurses. It was accompanied by a letter giving information about the study and asking the RN whether he or she was the best person to answer the questions in the particular municipality. The recipient had the opportunity to recommend another RN in their municipality, who was then contacted instead. The questionnaire

was open for six weeks, and three automatic reminders were sent by email during that period. It was not open to the public and was configured in such a way that each respondent could only answer the questionnaire once and could not change their answers after completing it.

3.5 | Statistical and content analyses

Descriptive and comparative statistics were used to analyse the cross-sectional data. Either the Pearson chi-square test or Fisher's exact test (if any expected cell value was less than 5) was applied when comparing nominal data between groups. The Kruskal–Wallis test was applied to compare ordinal data between the three groups. *p*-values below 0.05 were considered statistically significant. Where the results were statistically significant, the post hoc analyses were performed by means of the Mann–Whitney U test with the Bonferroni correction ($p = <0.017$). Analyses were performed using IBM SPSS Statistics version 24. The answers to the final open-ended question were read through several times before manifest content analysis of the text was applied (Bengtsson, 2016).

4 | RESULTS

Background characteristics, and the differences between the three groups of nurses are shown in Table 1. The MRNs with defined responsibility for LSS were significantly younger than the other MRNs and the LSS nurses. The group of LSS nurses had a significantly lower level of education (mostly three years of nursing education), less work experience and responsibility for fewer patients compared with the other groups (Table 1).

There were no differences between the groups of nurses about the organized collaboration with different care providers during the last year, or last three years, or about the collaboration for people with ID who have a specific somatic or psychiatric diagnosis (Table 2). The post hoc analysis showed non-significant results for the MRNs with defined responsibility for LSS compared with the other MRNs about experiences of organized collaboration with home care during the last year (*p*-value 0.024).

In the whole study group, 87% of the RNs perceived shortcomings in the collaboration with different care organizations (Table 2). These shortcomings were most common about inpatient psychiatric care (66%) and outpatient psychiatric care (47%). The results revealed statistically significant differences between the three groups of RNs about their perceptions of shortcomings in only outpatient psychiatric care (*p*-value 0.013). The post hoc analyses showed that more MRNs reported shortcomings than did LSS nurses (*p*-value 0.004), as did MRNs with a defined responsibility for LSS compared with LSS nurses (*p*-value 0.042).

The overall satisfaction with the collaboration between different care providers on both the regional and the municipal level was rather high (md 2–3 of most positive score 1) in all three groups, and there were no statistically significant differences (Table 3). All groups of nurses rated the collaboration with inpatient psychiatric care lowest, and the two groups of nurses with responsibility for LSS answered that it was rather bad. However, no differences were shown between the three groups of nurses when it comes to satisfaction with collaboration between different care providers (Table 3).

The presence of specific guidelines for health care for older people with multimorbidity and in need of support and care from both region and municipality is shown in Table 4. Of all nurses, 21% reported the presence of guidelines about organized collaboration between these two principal care providers for older people with ID. Local guidelines about collaboration between care providers for

TABLE 1 Characteristics of the study group of nurses

Background variables	All (N 110)	MRNs (N 67)	LSS nurses (N 19)	MRNs with LSS responsibility (N 24)	<i>p</i> ^a
Age					
Year, mean (range)	55 (34–66)	56 (34–66)	50 (34–63)	47 (42–65)	0.011
Gender, n (%)					
Women	100 (88)	63 (94)	17 (90)	20 (83)	0.770
Education, n (%)					
<3 years (university degree)	40 (37)	21 (31)	12 (63)	7 (29)	0.029
4–6 years (master's degree)	66 (60)	44 (66)	7 (37)	15 (63)	
Postgraduate degree	3 (3)	2 (3)	0 (0)	1 (4)	
Work experience as MRN/LSS nurse					
Years, mean (range)	7 (0–23)	8 (0–23)	5 (1–22)	8 (1–21)	0.045
Number of patients in area of responsibility					
Mean (range)	278 (0–3,000)	277 (0–1,500)	38 (5–70)	508 (0–3,000)	0.001

Abbreviations: LSS nurse, responsibility for people with ID receiving support in accordance with the LSS Act; MRN, Medically Responsible Nurse.

^aKruskal–Wallis test.

TABLE 2 The nurses' experiences of collaboration between different care providers concerning older people with ID in need of coordinated care

	All (N 110) n (%)	MRNs (N 67) n (%)	LSS nurses (N 19) n (%)	MRNs with LSS responsibility (N 24) n (%)	p ^a
Have had organized collaboration in the last year					
Inpatient psychiatric care	47 (43)	31 (46)	8 (42)	8 (33)	0.634
Outpatient psychiatric care	66 (60)	41 (61)	15 (79)	10 (42)	0.284
Inpatient somatic care	55(50)	37 (55)	9 (47)	9 (38)	0.187
Outpatient somatic care	54 (49)	37 (55)	9 (47)	8 (33)	0.090
Primary health care	83 (76)	51 (76)	17 (90)	15 (63)	0.176
Home care	65 (59)	45 (67)	10 (53)	10 (42)	0.042
Home help services	50 (46)	37 (55)	4 (21)	9 (38)	0.454
Private actors	38 (35)	23 (34)	6 (32)	9 (38)	0.615
Have had organized collaboration in the last three years					
Inpatient psychiatric care	50 (46)	34 (51)	6 (32)	10 (42)	0.520
Outpatient psychiatric care	51 (46)	31 (46)	9 (47)	11 (46)	0.498
Inpatient somatic care	48 (44)	31 (46)	6 (32)	11 (46)	0.777
Outpatient somatic care	48 (44)	30 (45)	7 (37)	11 (46)	0.703
Primary health care	67 (61)	46 (64)	9 (47)	15 (63)	0.270
Home care	57 (52)	37 (55)	5 (26)	15 (63)	0.055
Home help services	47 (43)	33 (49)	2 (11)	12 (50)	0.149
Private actors	31 (28)	20 (30)	2 (11)	9 (38)	0.238
More commonly with collaboration in respect of specific diagnoses					
Somatic diagnosis					
Epilepsy	25 (33)	18 (27)	2 (11)	5 (21)	0.982
Diabetes	35 (32)	25 (37)	3 (16)	7 (29)	1.000
Heart and lung diseases	28 (26)	18 (28)	2 (11)	7 (29)	0.322
Severe hearing and vision problems	16 (15)	12 (18)	1 (5)	3 (13)	0.881
Fall	26 (24)	18 (27)	2 (11)	6 (25)	0.717
Pain	31 (28)	22 (33)	2 (11)	7 (29)	0.822
Gastrointestinal diseases	16 (15)	10 (15)	1 (5)	5 (21)	0.444
Psychiatric diagnosis					
Schizophrenia	15(14)	11 (16)	2 (11)	2 (8)	0.593
Anxiety	21 (19)	16 (24)	1 (5)	4 (17)	0.322
Behavioural	30 (27)	20 (30)	2 (11)	8 (33)	0.117
Depression	15 (14)	10 (15)	1 (5)	4 (17)	0.711
Dementia	27 (25)	17 (25)	3 (16)	7 (29)	0.564
Organizations with largest shortcomings about collaboration^b					
Inpatient psychiatric care	72 (66)	46 (69)	12 (63)	14 (58)	0.623
Outpatient psychiatric care	52 (47)	36 (54)	4 (21)	12 (50)	0.013
Inpatient somatic care	36 (33)	19 (28)	10 (53)	7 (29)	0.167
Outpatient somatic care	12 (11)	7 (10)	4 (21)	1 (4)	0.261
Primary health care	35 (32)	21 (31)	5 (26)	9 (38)	0.533
Home care	2 (2)	2 (3)	17 (89)	19 (79)	0.528
Home help services	1 (1)	1 (2)	17 (89)	19 (79)	0.729
Private actors	10 (9)	5 (8)	3 (16)	2 (8)	0.587

Note: Statistically significant values are given in bold.

Abbreviations: LSS nurse, responsibility for people with ID receiving support in accordance with the LSS Act; MRN, Medically Responsible Nurse.

^aKruskal-Wallis test.

^bEach participant had the opportunity to choose a maximum of three different organizations.

TABLE 3 The satisfaction with collaboration between different care providers concerning older people with ID and in need of coordinated care (range 1–5^b)

	All (N 110) Md (Q1-Q3) ^c	MRNs (N 67) Md (Q1-Q3) ^c	LSS nurse (N 19) Md (Q1-Q3) ^c	MRNs with LSS responsibility (N 24) Md (Q1-Q3) ^c	<i>p</i> ^a
Overall, how well the collaboration between health care and social service works?	2 (2–3)	2 (2–3)	3 (2–3)	2 (2–3)	0.202
How well does the collaboration work?					
Inpatient psychiatric care	3 (3–4)	3 (3–4)	4 (3–4)	4 (2–5)	0.763
Outpatient psychiatric care	2 (2–3)	2 (2–3)	2 (2–3)	3 (2–5)	0.135
Inpatient somatic care	2 (2–3)	2 (2–3)	3 (2–3)	2 (2–3)	0.759
Outpatient somatic care	3 (2–3)	3 (2–3)	3 (2–3)	3 (2–3)	0.877
Primary health care	2 (2–3)	2 (2–3)	2 (2–2)	2 (2–3)	0.506
Home care	2 (1–2)	2 (1–2)	2 (1–2)	2 (1–2)	0.602
Home help services	2 (1–2)	2 (1–2)	2 (1–2)	2 (1–2)	0.916
Private actors	2 (2–3)	3 (2–3)	2 (1–3)	2 (2–3)	0.668

Abbreviations: LSS nurse, responsibility for people with ID receiving support in accordance with the LSS Act; MRN, Medically Responsible Nurse.

^aKruskal-Wallis test.

^bScore: 1 = very good, 2 = rather good, 3 = neither good nor bad, 4 = rather bad, 5 = very bad.

^cMd = median; Q1 = first quartile; Q3 = third quartile.

	N (%)
Guideline exists about organized collaboration between health care on regional and municipal level specific for older persons with ID	23 (21)
Applying national guidelines for CIP on older persons with ID	81 (74)
Have local guidelines for collaboration in the LSS specific for older persons with ID	6 (6)
Planning to construct local guidelines for collaboration specific for older persons with ID	11 (10)
Specific written guidelines for dementia assessment in older people with ID	15 (14)
Time for organized collaboration	Median (Q1-Q3)
Working with organized collaboration in number of years	10 (3–20)
Using CIP for older persons with ID in number of years	3 (1–4)

Abbreviation: CIP, Coordinated Individual Plan.

TABLE 4 Presence of specific guidelines for coordination of care (N 110)

older persons with ID were reported as present by 6% of the nurses. However, the national CIP guide for all adult people was reported as being used by 74% of the nurses.

Most present at the collaborative meetings were RNs (89%), followed by social service staff (82%). Less present were social workers (36%). Fifty-two per cent of the older persons with ID were present and nearly the same proportion of next of kin (Table 5). The results revealed that it was the RN's work organization that always or often took the initiative for collaborative meetings (total 57%), always or often was responsible for the performing of the meetings (70%) and always or often was responsible for the follow-up (68%) (Table 5). Of the nurses, 54% perceived that it was reasonable that their organization took the initiative for collaborative meetings, 51% perceived that it was reasonable that their organization was responsible for the performing of the

meetings and 45% perceived that it was reasonable that their organization was responsible for the follow-up.

The answers to the open-ended question about collaboration revealed that the nurses perceived challenges about communication and information delivery between care providers in the different care organizations, related to the secrecy regulations, which meant that the staff did not have access to one another's systems for documentation. It became clear that the nurses perceived that the care providers had too little knowledge of each other's activities and were unfamiliar with each other's organizations. That had a negative impact on collaboration and made it unclear which organization was responsible for which of the different tasks. Another challenge to collaboration reported by the nurses was related to physical collaborative meetings. Obstacles mentioned were lack of time and other care providers' limited interest in meetings (and not prioritizing them). Staff from the psychiatric clinic

TABLE 5 Implementation of the organized meeting for coordinated care (N 110)

	N (%)
Present at collaborative meetings	
Registered Nurse	98 (89)
Physician	57 (52)
Occupational therapist	69 (63)
Physiotherapist	58 (53)
Social worker	40 (36)
Staff from social service	90 (82)
Older person with ID	57 (52)
Next of kin	64 (58)
Legal guardian/Trustee	56 (51)
How often your organization is responsible for the initiative for collaborative meetings	
Always	10 (9)
Often	53 (48)
Sometimes	29 (26)
Seldom	9 (8)
Never	3 (3)
How often your organization is responsible for the performing of collaborative meetings	
Always	17 (16)
Often	59 (54)
Sometimes	22 (20)
Seldom	4 (4)
Never	1 (1)
How often your organization is responsible for the follow-up	
Always	19 (17)
Often	56 (51)
Sometimes	23 (21)
Seldom	2 (2)
Never	1 (1)

were less present, and GPs from primary health care. The lack of collaboration had an impact on the quality of care, since it was impossible for anyone to get a whole and clear picture of the often complex needs of the older person with ID.

The knowledge of each other's activities is inadequate, the focus is on organisations and not patients.

The nurses commented that specific guidelines for specific patient groups, such as older people with ID, were not necessary. They perceived that existing guidelines with CIPs for the general adult population were enough.

Guidelines in the municipality are designed to suit everyone and are not directed to special groups as there would then be far too many different guidelines.

5 | DISCUSSION

To the best of our knowledge, this study is the first to focus on the nurses' perception of collaboration for frail older people with ID in need of care from different care providers. The results showed that the three groups of nurses perceived collaboration in similar ways, independently of professional role and responsibility. A large proportion of the nurses identified shortcomings with regard to collaboration in the case of several care organizations, most commonly in the case of inpatient and outpatient psychiatric care. Furthermore, only about half of the people with ID and/or their next of kin participated in the care plan meetings. The results highlight the vital role played by nurses in the municipality in that they are the most common profession participating in the meetings for collaboration and the coordination of interventions from different care providers.

A common situation for frail older people with complex conditions and multimorbidity is that there are gaps in the continuity of care between short-stay hospital care and the support they need from the community (Ali & Rasmussen, 2004) and one of the frailest groups in society is people with ID (Kinnear et al., 2018; Northway et al., 2017; van Schrojenstein Lantman-de valk & Walsh, 2009). In this study, the group of LSS nurses were expected to be the most involved in the care of people with ID, due to their having fewer patients than the MRNs, whose responsibility covers all adult citizens in the municipality. However, our results did not confirm this expectation. A systematic review based on 27 published articles (Jaques et al., 2018) showed that the skills possessed by a specialist intellectual disability nurse are not different technically but uniquely relational, with increased patience and resilience in encountering people with ID. The nurses' communication with people with ID can often be a complex and time-consuming process, and the adverse consequences of underestimating the value of specialist skills in communication are serious and indeed potentially life-threatening (Jaques et al., 2018). Three statistically significant tasks are in focus for providing person-centred care: (a) providing education for persons with ID, hospital staff and families; (b) being an advocate (a credible ambassador) for the person with ID in the acute hospital setting; and (c) facilitating relationships between the person with ID, hospital staff and family to ensure better outcomes for health and well-being (Jaques et al., 2018). Our results indicate that all nurses in the municipality from their practical experience understand the vital role they must play in meeting the needs of older people with ID. The nurses' high rate of participation in the collaboration meetings can facilitate access to health care for people with ID. The use of patient passports and easier to read versions of patient information (including large bold font, pictures, photographs and symbols) ensures that people with ID obtain high-quality health care (Gates, 2006).

The RNs perceived that the collaboration worked rather well with other care providers even though there were some variations. A particular exception had to do with psychiatric care, and this result is in accordance with previous research, showing that collaboration, in general, is poor between psychiatric and other care providers. Some reasons mentioned in the literature are limited knowledge about

each other's systems such as updated phone lists, the opportunity of recurring consultations, unknown collaborative partners and time restrictions, and a different perspective on caring (Brändström et al., 2015; Fredheim et al., 2011). Furthermore, in a previous review involving comparison between specialist and general psychiatric care no clear evidence of best care was found (Chaplin, 2004). Improvement of collaboration and coordination with psychiatric care is essential since it has been found that older people with ID have more psychiatric diagnoses and receive inpatient and outpatient psychiatric specialist care more frequently than the general population (Axmon et al., 2018; Bhaumik et al., 2008; El Mrayyan et al., 2019, 2020).

Furthermore, in the open-ended answers, the nurses described obstacles to collaboration. One such obstacle was that the care providers lacked knowledge of each other's activities and were unfamiliar with each other's organizations, making it unclear which organization was responsible for which tasks. If the responsibilities and roles are unclear for the professionals, it can increase the risk of acute admission to hospital, delayed initiation of treatment and an extended stay in hospital (Washington et al., 2019), with decreased quality of life for the older people with ID. In a scoping review, the researchers found that professional care providers' knowledge of each other's competences and skills, appreciation of each other's roles, and trust and respect improved collaboration and the development of care plans (van Dongen, van Bokhoven, et al., 2016). Thus, there seems to be a need for education concerning interprofessional collaboration for all professionals partaking in collaborative meetings, including the advocacy role (Llewellyn & Nortway, 2007; Taggart & Mccinkey, 2001).

Other obstacles to collaboration mentioned by the nurses in the open question were related to organizational factors, such as lack of time for physical collaborative meetings, not having access to one another's systems of documentation, and laws and regulations. These obstacles to collaboration are well known and confirmed by previous research (van Dongen, van Bokhoven, et al., 2016; Légaré et al., 2013; Wodchis et al., 2015). Also, challenges about communication and information delivery were mentioned by the nurses. Previous research (van Dongen, Lenzen, et al., 2016) showed that care providers with different backgrounds did not have a common vocabulary: they used a discipline-specific language, which could not only serve as a barrier to collaboration between them but also exclude patients from understanding decisions and partaking in collaborative meetings.

Reference to the presence of and compliance with specific guidelines concerning collaboration between regions and municipalities was made only by 21% of the nurses. On the other hand, 74% mentioned CIPs for older people. This ambiguous result can be understood as indicating that nurses perceived guidelines on a policy level whilst the CIP is a tool for care on the individual level. The nurses commented that it was not necessary to establish specific guidelines for particular patient groups, such as people with ID. The MRNs are the ones who are responsible for the implementation of guidelines in practice, and it is plausible that guidelines for all adult citizens

facilitate the implementation. As regards the presence of staff at the collaborative meetings, the results reveal that nurses and staff from social services were most present and social workers least present. The nurses had a central coordinating function in that they had the main responsibility for organizing, performing and following up the care plan meetings. Responsibility for the initiation of care coordination through CIPs is shared by the organizations involved. However, nurses perceived the responsibilities as reasonable only in the case of about half of the meetings, but they complied to ease the process since it is usual for RNs to take on a coordinating role (van Dongen, Lenzen, et al., 2016; Metzethin et al., 2013). The social workers' low attendance is rather remarkable since social workers have an essential role to play in collaborative meetings. They are responsible for decision-making with regard to support and social service according to the LSS (Berglund et al., 2012; Larsson et al., 2020). However, for a well-functioning collaboration between different care providers from various organizations, it is essential that roles and responsibilities are defined and that all care providers work towards a common goal (van Dongen, van Bokhoven, et al., 2016; van Dongen, Lenzen, et al., 2016).

Ten years was the average time for organized collaboration and three years with CIPs in this study. However, just half (52%) of the people with ID and the next of kin (58%) were present at the collaborative meetings. This result is remarkable since the legislation requires participation by the individual to reach the goal of influence on the planning and delivery of care. Similarly, a recent review showed that the experiences of adults with ID with regard to involvement in care planning in health services are absent from the literature (Doody et al., 2019). It is imperative to listen to the people with ID inasmuch as their cognitive and communication difficulties make it challenging for them to identify their own health needs. A major goal of the care plans is enhancing communication, an important matter with any population but particularly for people with ID (Doody et al., 2019; Friese & Ailey, 2015). Since the decisions made during these meetings have direct consequences for the daily living of the older people with ID, these people's perspective is most important. If the older person cannot take part in the planning, a relative or guardian should take part on their behalf (van Dongen, van Bokhoven, et al., 2016; Foster et al., 2006; Talman et al., 2018). Care planning during collaborative meetings is a process where different professionals coordinate future care and social services *in interaction with* the older people with complex needs (van Dongen, van Bokhoven, et al., 2016). Previous studies have showed that older people need to be prepared before the collaborative meeting, told about its purpose (Kristensson et al., 2018), that staff have to use the patient's language (van Dongen, Lenzen, et al., 2016; Wodchis et al., 2015) and that the meeting should be held in a place where the older person can feel safe (Berglund et al., 2012). The strategies for causing the older person and close relative to become involved in the CIP, and barriers and facilitators concerning participation, are urgent questions to explore further in future research.

The results of this study indicate several new areas that need to be focused on in future research. One of them is the low degree

of participation of the people with ID and their next of kin in the care planning. Knowledge of barriers to such participation is necessary to design future intervention studies aimed to increase it. Here, an important role can be played by observations and by interviews with the nurses, the persons with ID and their next of kin. Another area for research involves conducting interviews with different professionals in psychiatric care to acquire a deeper understanding of how collaboration and coordination with the medically responsible RNs in the municipality can be developed. Lastly, there is a need to develop a specialist education for the LSS and MAS nurses and to evaluate the effect of this education on the quality of older people care and integrated health care. The older person with ID needs health care on equal terms with the general older population, which is facilitated by higher competence of nurses.

5.1 | Methodological considerations

Some methodological strengths and weaknesses need to be considered when interpreting the results of the study. It was designed as a national survey study concerning a previously neglected area in the intellectual disability service and in healthcare research (Gates, 2006). A survey as a research method identifies areas that often need to be followed up to acquire a deeper understanding of the identified phenomena. One limitation of the study is that the overall dropout rate was 178 of 290 municipalities (61%), which reflects the voluntary nature of participation. The relatively high attrition rate may affect the generalization of the results, which the reader should keep in mind. The number of LSS nurses was only 19, which was lower than expected. There are various conceivable reasons for dropout, including limited time for answering the questionnaire due to heavy workload, not working with organized collaboration and lack of familiarity with answering questionnaires online. According to Swedish ethics legislation, voluntary participation in a research study means that researchers are not allowed to ask the reason for non-participation. This was applied in this national survey study.

The lack of psychometric testing of the questionnaire is also a key limitation, which means that the reliability and validity of the survey are not known. However, the process of constructing the questionnaire was comprehensive, involving several seminars, literature review and use of clinical experiences. The interdisciplinary team included researchers skilled in developing measures, psychometric testing, geriatric and intellectual disability research. Due to the lack of psychometric testing, each question is seen as a single item and not as part of a scale or index. Psychometric testing of the questionnaire is necessary before it can be recommended for use in future studies. The survey used in this study is to the best of our knowledge the first one to be directed towards the development of instruments for evaluating the collaboration and coordination required for integrated care for frail older people with multimorbidity such as those with ID.

6 | CONCLUSIONS

This study contributes unique knowledge about nurses' perception and vital role of the coordination of care between different care providers in respect of older people with ID. The nurses were satisfied with most collaborations and applied the guidelines designed for all adult citizens, not wanting specific guidelines for older people with ID. The implementation of regulations with regard to making coordinated individual care plan needs to be strengthened through increased participation of older people with ID at the care plan meetings. Their presence and perspective are necessary for the implementation of coordinated person-centred care and the reason for their not being present at the meetings ought to be further explored in future research. The reason why the social workers attended much more seldom needs to be further explored. The shortcomings in collaboration had to do with inpatient and outpatient psychiatric care. Since staff in psychiatric care play an essential role in the collaboration about older people with ID, it is of interest to further explore collaboration from their perspective to develop a supporting programme for improved collaboration.

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CONFLICT OF INTEREST

The authors declare that they have no competing interests.

AUTHOR CONTRIBUTIONS

GA designed the study and developed the questionnaire in close collaboration with MP, JK and IR. GA was responsible for applying for external funds. GA drafted the manuscript together with J-ÅH. CB conducted the analysis and wrote parts of the manuscript. All authors read, discussed and approved the final version of the manuscript.

ETHICAL APPROVAL

The research project is guided by the ethical principles for medical research (the Declaration of Helsinki). The information letter explained the purpose of the study and pointed out that participation was voluntary and they could at any time withdraw from the study without giving a reason. It further informed them that by sending in the survey, they also had consented to participate in the study. The participants were guaranteed confidentiality by the presentation of the results at group level. The STROBE checklist for cross-sectional studies was applied (Appendix S1).

DATA AVAILABILITY STATEMENT

Even though the data are anonymized, the study contains sufficient details to enable the identification of individuals. The questionnaire and data are available from the project leader (GA) on reasonable request.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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