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RESEARCH PAPER

Communication intervention in Rett syndrome: a survey of speech language pathologists in Swedish health services

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Abstract

Purpose: To investigate communication intervention that speech language pathologists (SLPs) provide to people with Rett syndrome. **Methods:** A web-based survey targeting all Swedish SLPs working with people currently receiving support from habilitation services. **Results:** The SLPs reportedly followed recommended practice in the following aspects: (1) Information on communicative function was collected from several sources, including observation in well-known settings and reports from the client's social network, (2) Multimodal communication was promoted and, (3) Responsive partner strategies were largely targeted in the intervention. However, few instruments or standard procedures were used and partner instruction was given informally. Most SLPs used communication aids in the intervention and their general impression of using communication aids was positive. Further, augmentative and alternative communication (AAC) was estimated to increase and clarify communicative contributions from the person. **Conclusions:** Communication aids were reported to have a positive influence on communicative functions. Swedish SLP services followed best practice in several aspects, but there are areas with potential for development. Tools and best practice guidelines are needed to support SLPs in the AAC process for clients with Rett syndrome.

Keywords

Augmentative and alternative communication, communication, intervention, Rett syndrome, speech language pathology, Sweden

History

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► Implications for Rehabilitation

- Communication aids were reported to increase and clarify communicative contributions from people with Rett syndrome.
- Systematic procedures and instruments for assessment, evaluation and partner instruction were used to a small extent.
- A limited range of communicative functions were targeted in the interventions.
- There is a need for developing best practice guidelines to support SLPs in the AAC process for this population should be clients with Rett syndrome.

Introduction

Rett syndrome is a genetically based disorder almost exclusively affecting females with an estimated prevalence rate of 1/10 000 females. After a seemingly uneventful infancy, a regression period occurs with a loss of previously achieved skills, such as babbling or speech and voluntary hand movements. The condition stabilises but severe and multiple disabilities remain, among those, significant communicative difficulties [1–3]. Augmentative and alternative communication (AAC) consists of a wide range of methods and strategies to enhance communication when spoken language is insufficient for communicative needs, regardless of

diagnosis. AAC comprises both unaided forms (e.g. signs and gestures) and aided forms (e.g. pictures, objects and speech-generating devices) [4]. Strong evidence exists suggesting that both aided and unaided AAC interventions can increase the number and effectiveness of communicative acts as well as facilitate communicative, social and linguistic development [5–10]. AAC strategies have been found to have a positive impact on communication skills of people with various disabilities, including Rett syndrome [5,11–13]. Previous studies indicate predominantly pre-intentional communication among people with Rett syndrome. There are, though, recognised difficulties in formally assessing abilities in these individuals [14–16]. Studies in which alternative ways of expression have been used indicate that intentional communication is more common than previously expected. Use of communication aids such as graphic symbols seems to be a promising way to elicit more specific and intensive communicative acts, especially with eye gaze access [14,17–20]. Further, clinical reports suggest a higher linguistic and communicative level than formerly believed

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in individuals with Rett syndrome who get access to aided communication [21,22]. More recent studies using parent reported data also support a higher receptive language ability than suggested by earlier studies [23,24]. Regardless of target group or AAC form included in the intervention, functional communication is important to researchers, practitioners and people using AAC [6,25–27]. Interventions are often restricted to expressing wants and needs. However, other functional goals, such as sharing information and social interaction, have been stressed [6,28–30]. Joint attention and a responsive communicative style in interaction partners have been found to be closely connected to early communication development [31–33]. Other common findings are that many individuals need a multimodal communication system that includes different forms of AAC. Several studies therefore include both aided and unaided communication [5,12,34]. For individuals with restricted motor abilities, unaided forms (e.g. signs and gestures) are not accessible, which increases the need for aided communication. The use of communication aids has been shown to increase the positive effects of the intervention [5]. However, there seems to be no support in favour of any specific type of communication aid [5,35,36]. The design of the AAC system should thus be based on individual needs. The fit between communication aids and the persons using them has been identified as important for implementation [37].

Numerous studies have acknowledged that the communication partners are important in assessment and implementation of aided communication [4,19,38–40]. Stakeholders, such as parents, have expressed a need for more support in choosing and implementing AAC methods [41,42]. There are indications that people who would benefit from aided communication do not receive these services or that communication aids are abandoned, even though the need for AAC remains [43–45]. Factors (such as competence and team dynamics) related to the service system have been proposed to contribute to this fact [37,46]. The heterogeneity of consumers makes the AAC field complex and the technical progression is fast-paced. The demands for professionals to be adequately prepared for various individual needs and to keep up with technical progress are taxing.

In many countries, speech and language pathologists (SLPs) have a central function in AAC assessment and education. However, previous findings suggest that SLPs perceive a lack of AAC competence as well as a need for more knowledge of AAC [47–50]. A conclusion of previous work on AAC services provided by SLPs is that there seems to be people with communication disabilities that are not provided any aided communication. It is also evident that there are regional and individual variations in practice, as well as pre-service education and the formal organisation of SLPs working with AAC methods [43,44,48,49,51–54]. In Sweden, the SLPs providing services to people with Rett syndrome are frequently part of teams supporting people with a wide range of disabilities. Some SLPs, however, work in teams specialised in aided communication or communication devices that serve a county council or a larger region. The county councils and municipal authorities are largely autonomous, which enables local variations across the country. Consequently, differences exist regarding assistive technology provision between county councils [55,56]. However, the local health care services are supervised by the National Board of Health and Welfare (Swedish: Socialstyrelsen), a government agency that pursues equal access to health care for all citizens. The central government establish principles and guidelines for health care services but guidelines for aided communication are still lacking.

Our knowledge on how common use of communication aids is among people with Rett syndrome is inconclusive. In one study,

no children or adults with Rett syndrome were reported to use communication aids as a means for communication [57], whereas in another survey study, one-third of Swedish parents reported that their children used some sort of communication aid [58]. An even higher rate of communication aids was reported in an international survey from 2010 [24]. Picture or symbol communication boards were used to communicate by 61% of girls with Rett syndrome and over 40% reported unspecified devices. In von Tetzchner et al. [59], approximately 50% of the participating parents reported that their children received aided communication intervention. The two most commonly used aids were objects/pictures of reference and visual support, followed by single message electronic devices.

It is of interest to examine aided communication services provided to people with Rett syndrome. In supporting communication and communicative development SLPs deal with difficulties in assessing abilities, inconsistency in functioning in different situations and daily variations. Because of the low prevalence of Rett syndrome, most SLPs are likely to meet only a few individuals in their clinical practice. To tailor intervention strategies and assessment routines that work in everyday settings we need to learn more about how SLPs work. The aim of this study is therefore to explore the service provided to people with Rett syndrome by Swedish SLPs working in various habilitation settings. Specific research questions were:

- Which intervention methods are used to assess and evaluate communication in Rett syndrome?
- What are the overall aims, formats and estimated outcome of general communication intervention for people with Rett syndrome?
- What are the formats and estimated outcome of communication intervention with communication aids for people with Rett syndrome?

Methods

The study was a survey with a cross-sectional descriptive approach.

Target group

The survey targeted all licensed Swedish SLPs working with people receiving support from habilitation services at the time the survey was initiated. Participants in this study were the respondents who reported that they worked with aided communication and who had provided communication intervention to at least one client with Rett syndrome.

Instrument

The study-specific web-based questionnaire (SPEAC-GR – Speech Language Pathologists' Experiences of Aided Communication Generally and in Rett Syndrome) was developed for the study. The questions were based on previous research and the first author's clinical and professional experience, as well as on knowledge of Swedish current clinical practice. Items were also acquired from the SLPAQ-84, which is used to examine how SLPs work with people with aphasia [60]. The development of the questionnaire was performed in three steps. Initially, a pilot paper version of the questionnaire was filled out by three non-SLP practitioners (music therapist, social worker and occupational therapist) to check the clarity of the questions. In the second step, three clinically experienced SLPs investigated the face validity of the revised pilot paper version. In the third step, the adapted web questionnaire was tested by 10 PhD students and researchers to address specific issues connected with the questionnaire being web based.

After adjustments, the final version of the SPEAC-GR consisted of four sections. Section one covered demographics and work task-related data (15 items) and section two consisted of questions about aided communication intervention in general (10 items). Section three targeted only SLPs who had provided communication intervention to one or more individuals with Rett syndrome. This section covered background data on the person with Rett syndrome, information about time frames and aims, formats and outcome of general communication intervention (16 items). Section four addressed specifically aided communication intervention provided to people with Rett syndrome (e.g. specific communication aids used, outcome and what factors the SLPs believed facilitated or hindered implementation of the communication aids used in the intervention; 8 items). In sections 3–4 (covering Rett syndrome), the respondents were asked to provide their answers with reference to their latest intervention involving a client with Rett syndrome. This procedure was assumed to provide the most valid information.

The format of the questions was fixed response alternatives or numeric textboxes. When the respondents chose the alternative “other”, they were asked to specify their choice. Two questions covering facilitating and hindering factors for implementation of aided communication were open-ended. In this article, quantitative results from section three and four are presented.

Web survey tool

The on-line survey tool used for the web version was SurveyMonkey [61]. All e-mails included a link to remove the recipient's e-mail address from the send list. Adaptive questioning was used.

Participants and procedure

Recruitment and data collection procedure

In an initial step, e-mail addresses to SLPs ($n = 320$) working at habilitation and technical aid centres were identified through manual search of the Swedish county council's web pages. These SLPs were then asked to provide additional e-mail addresses to SLPs they considered were missing on the send list to identify SLPs working in other settings such as schools or city councils. The final send list consisted of 352 SLPs (Figure 1) who were sent a cover letter with information on the study and the questionnaire and a link to the SPEAC-GR. A first reminder was sent after approximately 14 days and a second reminder after 1 month.

Participants

The participation rate was 67% ($n = 236$). In all, 205 respondents working with aided communication answered the qualifying

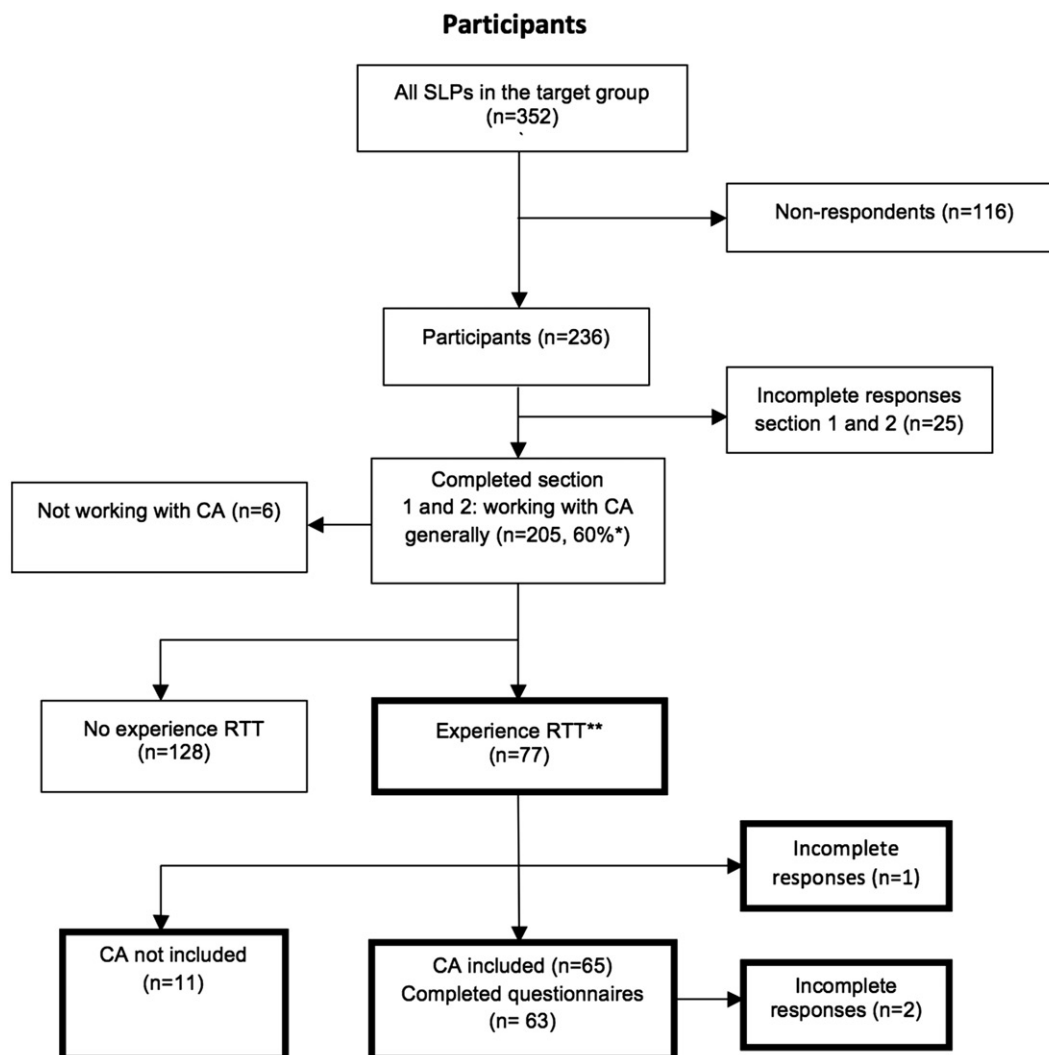


Figure 1. Flow chart over participants. SLP, speech language pathologists; RTT, Rett syndrome; CA, communication aid. *Percentage of all SLPs in the target group: SLPs working with people currently receiving support from habilitation services. **Participants in this study.

question to this study (Figure 1). The participants in this study consist of 77 SLPs with experience of working with at least one individual with Rett syndrome.

Non-respondent analysis

Of the 116 non-respondents to the total questionnaire, 44 SLPs (38%) were employed in a single county council where the SLPs were explicitly asked by their employers not to answer during work hours. No other possible sources of bias were identified. All 236 respondents answered the first eight questions about gender, age or length of experience in the profession. Twenty-five respondents did not complete the first two sections of the SPEAC-GR. Analysis using the Mann–Whitney *U* test and Pearson's chi-square test showed that these participants did not differ in sex, age or length of experience from those who completed section one and two.

Analysis

Data from the survey were provided by the web survey service as an Excel spread sheet that was imported to SPSS version 20.0 (IBM Corp., Armonk, NY) [62]. Descriptive statistics were used in the analysis of quantitative data. Results are presented as frequencies and percentages. In the presentation of the results, some of the ordinal scale responses were collapsed when a more detailed division did not provide any additional information. For example, the option "exclusively" was collapsed with the option "to a large extent".

Ethical considerations

Ethical regulations and guidelines were followed according to Swedish Law 2003:460 [63], based on the WMA declaration in Helsinki [64]. The participants received written information about the study, were told that participation was voluntary and that their answers could not be linked to any specific e-mail address.

The number of people with Rett syndrome is limited. It might therefore be possible to identify the participants as well as the persons with Rett syndrome by information on the SLPs location. One of the main reasons for choosing a web version was that reminders could be sent without the possibility to trace back individual responses to any specific e-mail address. Participants provided informed consent upon returning the questionnaire.

Results

All results are reported item wise.

Participants

The mean number of years of clinical experience of the 77 participants was 13.9 years. Work-related experience ranged from 0 to 40 full years (refer Table 1 for details of work experiences and intervention time frames). Five work settings were reported and 29% worked in more than one setting. Children habilitation centre was the most commonly reported setting (64%), followed by adult habilitation centre (42%), communication centre (14%), technical aid centre (5%) and pre-school/school/daily care centre (1%). Half of the respondents had met one single person with Rett syndrome sometime during their career as an SLP. The majority of the respondents had been in contact with the patient or the social network within the past three years and 80% reported that the total length of contact was 0–3 years. Most SLPs (66%) had been in contact with the client or the social network within 12 months before answering the questionnaire. Sixteen per cent reported that the latest contact occurred 1–3 years before responding and 18% reported that the latest contact took place

over 3 years before the questionnaire was sent. Two of the participants stated that their answers concerned a patient that they considered atypical for the population group. The reasons given were that the patient had more motor and cognitive abilities in one case and less motor and cognitive abilities in the other case.

Methods for assessment and evaluation in communication intervention

Seventy-seven SLPs provided information on assessment and evaluation procedures. The most common approach was information from the social network of the person with Rett syndrome ($n = 72$, 94%) and observation ($n = 72$, 94%), followed by direct interaction ($n = 45$, 58%). The observations were made in different settings, i.e. places well known to the person with Rett syndrome (e.g. home or at school) or less well known (e.g. a habilitation centre). The observations were also made with different interaction partners (familiar to the person with Rett syndrome (a parent) or less familiar (another therapist)). Seventy percent of the SLPs based their assessment on three or more sources of information.

Seventy-six participants responded to questions about instruments and tools used in assessment and evaluation. Sixty-five percent of the respondents reported that no instruments were used during the intervention. Self-constructed protocols or checklists were the second most frequent response (39%). The process-oriented instruments "Collaborative problem solving" [65] and the GAS (Goal Attainment Scale) [66] were used by 12 (16%), respectively, 1 (1%) of the participants. Other instruments were reported by 10% of the participants. Of those, the Swedish checklist StAKK (Startvaska for AKK) [67,68] was most frequently reported (4%). Other instruments specified were checklists used in Hanen Programmes [69], Marte Meo [70] and SECDI [71]. In the comments, 16 (21%) of 76 SLPs stated that they had been involved only during a limited part of the AAC process. Of these 16 SLPs, five had recently started the contact and three stated that they had only a counselling role.

Table 1. Background data on participants' work experience and intervention time frames ($n = 77$).

	<i>n</i> (%)
Work experience (years)	
0–4	14 (18)
5–9	22 (29)
10–14	12 (16)
15–19	9 (12)
20–40	20 (26)
Number of clients with RTT	
1	37 (48)
2	23 (30)
3	14 (18)
4–5	3 (4)
Estimated number of appointments with the client or social network	
1–5	38 (49)
6–10	17 (22)
11–15	8 (10)
16–20	5 (6)
>20	9 (12)
Estimated total length of contact with the client or social network (years)	
0–1	36 (47)
2	13 (17)
3	12 (16)
4–10	14 (18)
11–25	2 (3)

Aims of general communication intervention

Interventions targeted all the communication functions that were specified in the questionnaire (Table 2). Functions used to express wants and needs, were focus for the intervention “to a large extent/exclusively”, i.e. choice-making (76%) and requesting (61%). These functions were followed by two of the basic functions in the communicative category “interaction”, namely, turn taking (28%) and joint attention (26%).

The more linguistically charged functions in the communicative category “conversation” were reported not being targeted at all by several of the respondents: asking (53%), followed by commenting (45%), narrating (45%) and initiating topic (42%). The communicative functions imitating (communicative category; interaction) and following instructions (communicative category; show understanding) often involve voluntary motor actions and were reported not being targeted at all by 50 and 30% of the SLPs, respectively.

Partner strategies targeted in general communication intervention

A variety of partner strategies were included in the intervention and all participants reported at least one partner strategy as target for the intervention. The results are presented in Table 3. Most SLPs (71%) focused on Provide opportunities for choice making “to a large extent/exclusively” (in the category Eliciting specific actions). Responsive strategies were commonly reported to be targeted in interventions “to a large extent/exclusively”: namely, “Acknowledge and confirm expressions” (68%), “Give time” (63%) and “Attend to expressions” (61%). The strategy “Identify

motivating activities” in the category “Behaviour state regulation” was also frequently reported (67%).

Instruction used in general communication intervention

The interaction partners were most often instructed informally in conversation (“to a large extent” by 66% of the SLPs and “exclusively” by 15%). Modelling was used to instruct the social network “to a large extent/exclusively” by 32% and instruction or feedback in interaction with the person with Rett syndrome was used “to a large extent/exclusively” by 26% of the SLPs. The instruction modes reported not used at all by most SLPs were instruction films (86%), role play (83%) and instruction/feedback on recorded interaction with the person with Rett syndrome (71%).

Evaluation of general communication intervention

The interaction partners were estimated to use facilitating strategies “totally/to a large extent” by 28 (37%) of the respondents, “partly” by 23 (30%), “not at all/to a small extent by 9 (20%) and 16 (21%) had not evaluated that aspect. The communicative ability of the person with Rett syndrome was estimated to have developed totally/to a large extent by 10 (13%) of the respondents, “partly” by 24 (32%), not at all/to a small extent by 24 (32%) and 18 (24%) responded “don’t know”.

Formats and estimated outcome of intervention with communication aids

Of the 76 SLPs who completed part three (Communication intervention in Rett syndrome), 66 (87%) reported that the

Table 2. Communicative functions targeted in general communication intervention ($n = 76$).

Communicative category	Communicative functions	Not at all n (%)	To a small extent/partly n (%)	To a large extent/exclusively n (%)
Interaction:	Imitating	38 (50)	28 (37)	10 (13)
	Joint attention	14 (18)	42 (55)	20 (26)
	Turn taking	18 (24)	37 (49)	21 (28)
Expressing wants and needs:	Choice making	–	18 (24)	58 (76)
	Requesting	5 (7)	25 (33)	46 (61)
Conversation:	Asking	40 (53)	25 (34)	11 (15)
	Commenting	34 (45)	28 (37)	14 (18)
	Initiating topic	32 (42)	32 (42)	12 (16)
	Narrating	34 (45)	30 (39)	12 (16)
Show understanding:	Following instructions	23 (30)	46 (61)	7 (9)
Other:	Other communicative function ^a	58 (76)	9 (12)	9 (12)

^aExample of other communicative functions as specified by the respondents: taking more initiatives, linguistic competence, joking, answer yes/no.

Table 3. Partner strategies targeted in general communication intervention ($n = 76$).

Category of partner strategy	Partner strategy	Not at all n (%)	To a small extent/partly n (%)	To a large extent/exclusively n (%)
Behaviour state regulation:	Catch attention, regulate arousal	9 (12)	31 (41)	36 (47)
	Identify motivating activities	3 (4)	22 (29)	51 (67)
Responsive strategies:	Acknowledge and confirm expressions	4 (5)	20 (26)	52 (68)
	Attend to expressions	5 (7)	25 (33)	46 (61)
	Give time	4 (5)	24 (32)	48 (63)
Eliciting (specific) actions:	Expectant delays	10 (13)	28 (37)	38 (50)
	Model communication	9 (12)	31 (41)	36 (47)
	Provide opportunities for choice making	4 (5)	18 (24)	54 (71)
Other:	Other partner strategies	–	6 (7)	5 (7)

Table 4. Communication aids (CA) included in the intervention and perceived usefulness by SLPs ($n = 64$).

Communication aids	CA included in the intervention	Useful n (%)	Not useful n (%)	Useful: CA included ^a n (%)	Not useful: CA included ^b n (%)
Pictures/objects of reference	52 (81)	47 (73)	5 (8)	47 (90)	5 (10)
Visual support	42 (66)	37 (58)	5 (8)	37 (88)	5 (12)
Single message electronic devices	34 (53)	30 (47)	11 (17)	30 (73)	11 (27)
Communication charts/books	30 (47)	22 (34)	8 (13)	22 (73)	8 (27)
Computer with eye gaze access	24 (38)	19 (30)	5 (8)	19 (79)	5 (21)
Communication passport	16 (25)	10 (16)	6 (9)	10 (63)	6 (38)
PECS	19 (30)	4 (6)	5 (8)	4 (44)	5 (56)
Computer with other access options	15 (23)	7 (11)	8 (13)	7 (47)	8 (53)
Miscellaneous CA	13 (20)	10 (16)	3 (5)	10 (77)	3 (23)
Talking mat	6 (9)	4 (6)	2 (3)	4 (67)	2 (33)
Communication apps	5 (8)	3 (5)	2 (3)	3 (60)	2 (40)
Multi-message electronic devices	3 (5)	–	3 (5)	–	3 (100)

Eleven SLPs responded that the intervention did not include communication aids. One non-respondent.

^aPercentages are based on the participants that had used the specific communication aid in the intervention.

^bPercentages are based on the participants that had used the specific communication aid in the intervention.

Table 5. SLPs' reports of how communication aids contributed to the communication of the person with Rett syndrome ($n = 64$).

Communicative category	Communicative function	More seldom or less clear n (%)	No effect n (%)	More often or more clear n (%)	Don't know n (%)
Interaction:	Imitating	8 (13)	13 (21)	13 (21)	29 (46)
	Joint attention	4 (6)	6 (10)	25 (40)	28 (44)
	Turn taking	2 (3)	8 (13)	28 (44)	25 (40)
Expressing wants and needs	Choice making	3 (5)	3 (5)	46 (73)	11 (18)
	Requesting	3 (5)	8 (13)	31 (49)	21 (33)
Conversation	Asking	3 (5)	22 (35)	9 (14)	29 (46)
	Commenting	5 (8)	21 (33)	7 (11)	30 (48)
	Initiating topic	3 (5)	20 (32)	10 (16)	30 (48)
	Narrating	4 (6)	24 (38)	5 (8)	30 (48)
Show understanding	Following instructions	2 (3)	12 (19)	20 (32)	29 (46)
	Showing anticipation	1 (2)	6 (10)	36 (57)	20 (32)
Other ^a	Other communicative function		8 (13)	6 (10)	49 (78)

^aExamples of other communicative functions that were specified: Answering yes/no, having more influence in daily life, overall participation.

intervention included communication aids. Of these, 77% reported that the person with Rett syndrome used gaze to indicate and 45% reported hand/fingers/finger as the indication mode. Several types of communication aids were included in the intervention according to the SLPs. These are presented in descending order of frequency in Table 4, with pictures/objects of reference as the most frequently used communication aid, followed by visual support and single message electronic devices.

Of the communication aids reported, most (60–90%) were estimated to be “useful” (Table 4). Fewer of the respondents reported the alternatives that are more demanding on motor functioning to be useful: Picture Exchange Communication System (PECS; 44%), computer with other access options (than eye gaze; 47%). Multi-message electronic devices were not reported to be useful by any SLP.

Most (94%) of the interventions included trials with at least two or more of the specified communication aids and 59% included at least four aids. The largest part of the AAC systems used was thus multimodal.

The SLPs were also asked to estimate how communication aids influenced the person with Rett syndrome's communicative contributions concerning different communicative functions. The results are reported in Table 5. The SLPs reported that the communication aids allowed the persons with Rett syndrome to

more frequently or effectively contribute to the communicative categories interaction, express wants and needs and show understanding. The person targeted in the interventions was reported to more often or clearly perform choice making (73%), show anticipation (57%), request (49%), participate in turn-taking (44%) and engage in joint attention (40%) when communication aids were used. Communicative functions in the category “Conversation” were reported to a lesser extent. The percentage of SLPs who chose the option “Don't know” for the specified communicative functions ranged from 18% to 48%.

Forty-seven percent of the SLPs estimated that the persons with Rett syndrome used their communication aid “to a large extent/always” in one everyday setting (Table 6). Forty percent of the SLPs reported that the persons with Rett syndrome used their communication aid “to a large extent/always” with more than one interaction partner.

Discussion

The purpose of this study was to survey SLP services provided to people with Rett syndrome in relation to communication. To the best of our knowledge, no previous study has been conducted focusing SLPs' view on communication intervention provided to this target group.

Table 6. Estimated outcome of communication intervention with communication aids ($n = 63$).

SLP-estimated outcome	Not at all n (%)	To a small extent/ partly n (%)	To a large extent/ always n (%)	Don't know n (%)
The person with RTT used CA in one everyday setting ^a	2 (3)	19 (31)	29 (47)	12 (19)
The person with RTT used CA in more than one everyday setting	11 (17)	25 (40)	15 (24)	12 (19)
The person with RTT used CA with more than one interaction partner	2 (3)	22 (35)	25 (40)	14 (22)
CAs were perceived to work satisfactory according to the social network	1 (2)	23 (37)	21 (33)	18 (29)

RTT, Rett syndrome; CA, Communication aid.

^aOne participant did not respond to this question. The percentage is therefore based on 62 participants.

Communication aids used in intervention

According to the present results, most communication interventions included communication aids (87%). Half of the respondents estimated that communication aids were used to a large extent in at least one everyday setting. This finding can be compared with the study of Didden et al. [57] in which none of the participants reported that the girls with Rett syndrome used communication aids. These differences should be viewed with caution, however, because the methodologies in the studies differ. In this study, SLPs were asked to report whether communication aids had been used in intervention, whereas in the study by Didden et al. parents were asked to give examples of how their daughters expressed different communicative functions in everyday life. In a previous Swedish survey study, one-third of the participating parents reported that their children with Rett syndrome used communication aids [58].

The two most commonly reported aids were pictures/objects of reference and visual support, and thereafter single message electronic devices. Pictures/objects of reference were also mentioned as the most common way to use pictures in von Tetzchner et al. [59]. Single message devices fall into the category low technological options, which have been provided more often than high technological options by SLPs to people with various disabilities [44,48,52]. However, in this study, computers with eye gaze access had been included in the intervention by 38% of the SLPs and were considered to work well compared with other high technology options. This observation supports the increasing evidence for eye gaze access as a useful way to indicate for the target population [18,71,72]. In a previous study of communication aids provided to and accepted by children with Angelman syndrome, the parents reported more complex communication aids to work well [73]. One reason given was that more complex aids allowed the children to express a more extensive vocabulary. Interventions using computers with eye gaze options with people with Rett syndrome is an interesting subject for further research. The respondents generally considered the communication aids included in the intervention to work well, supporting previous findings that communications aids enable clients with Rett syndrome to show more communicative and linguistic competence than in unaided communication [14,17–19]. Exceptions in this study were consequently communication aids demanding a higher level of motor control (PECS, multi-message electronic devices and applications on computers with other control options than eye gaze).

Communicative functions

Choice making and requesting (expressing wants and needs) were by far the most common intervention targets (Table 3). It is thus not surprising that these were the communicative functions that

were most frequently reported to be positively affected by the use of communication aids. This was also found in the study by von Tetzchner et al. [59], where choice making and understanding what will happen next were the reported main areas for aided communication intervention. However, in our study, communication aids reportedly also had a positive influence on communicative functions in the category interaction, i.e. turn taking and joint attention. These are both considered important for communicative development [31–33]. Interestingly, interaction was not frequently targeted in intervention. Aims in the communicative category conversation (commenting, asking, narrating and initiating topic) were focused on only to a small degree, which is consistent with previous studies of other populations [28]. In Koppenhaver et al. [19] access to communication aids was found to increase the frequency of commenting and labelling by girls with Rett syndrome in the context of story-book reading. Arguments for providing opportunities and supporting a wide range of communicative functions have been brought forth by other authors [28,30,74]. A strong social interest has been reported in many persons with Rett syndrome [75], which warrants further research on interaction and conversation as targets in intervention.

The role of the social network

The present results indicate that the social network was highly involved in the intervention, i.e. by providing information in assessment and evaluation. Observations for the purpose of assessment and evaluation included settings well known to the client as well as interaction with familiar partners. Researchers have emphasised the importance of participation by the social network during the AAC assessment process and assessment in natural settings [26,27,46]. Two studies have shown that SLPs acknowledge the important role of everyday interaction partners in the AAC process [54,76]. However, few studies of SLPs' AAC practice provide information about the role of everyday interaction partners during the process. The sole exception is families' negative attitudes toward AAC as a barrier for implementation [44,45]. In one previous study, the participating SLPs reported that assessment and evaluation were based on clinical impressions and observations in clinical settings [51]. All participants reported that at least one partner strategy was targeted in the intervention, suggesting that the interventions reported in this study were aimed at enhancing the communicative social environment.

Informal assessment and instruction

A shortage exists of suitable standard protocols in AAC assessments. As they rely heavily on voluntary actions, the existing instruments need to be adapted to people with Rett syndrome. The infrequent use of instruments reported in this study confirms the

paucity of suitable standard instruments, although there are instruments of potential clinical value, such as IPCA [57], RAACS [77] and CCCP [78]. Further studies on the aforementioned instruments used in clinical contexts would be warranted. In recent years, systematic instruction of the interaction partners has gained more attention. According to Kent Walsh et al. [79], strategic instruction, including several evidence-based components, increases the chances that facilitating partner strategies are used and generalised on a long-term basis. However, informal conversation was by far the most common mode of instruction as reported by the SLPs in this study supporting earlier findings from other study populations [73]. Programmes aimed at empowering and enhancing the communicative knowledge and skills of parents have been developed for a general population and some specifically modified for persons with Rett syndrome [38,68,80–82]. Use of programmes or other systematic instructions has been promising in increasing the implementation of aided communication in other populations [83]. The use of communication aids was reported by many of the participants to be restricted to one everyday setting. One interpretation of these results is that the interventions were recently started. The results might somehow indicate a need for more elaborated forms of instruction and methods to involve a larger part of the social network.

Swedish context

When interpreting the present results, the Swedish health care context should be considered. As described in the introduction, policies for assistive technology have been found to vary across the country [56]. Such variation was not examined in this study but might be reflected in the results. It would be of interest to investigate and highlight policies across the country regarding high technological options, e.g. computers with eye gaze access.

Clinicians with varying experience of AAC have been found to perform and view AAC service differently [40,43]. Binger et al. [46] identified three types of SLP involved in the AAC process: the general practice SLP, the AAC clinical specialist that typically spends more than 50% of the work time on AAC-related activities, and the AAC research/policy specialist. The participants in this study consist of SLPs with a varying level of experience and specialisation that cannot be directly translated into the groups defined in the aforementioned studies. An estimate is that the participants are more similar to AAC specialists than to general practice SLPs because they only work with clients with disabilities. All participants also reported functional goals, a pattern found to be typical for AAC specialists [52]. A further topic of research would be to examine Swedish SLPs experience and level of specialisation in AAC.

To explore whether there are cultural differences between countries that might affect communication intervention provided in different countries was outside the scope of this study. However, it would be of interest for further research in that an increasing number of studies involve people with Rett syndrome from several countries [24].

Methodological considerations

The main threat to validity for this study is recollection errors. However, a large proportion (66%) of the respondents reported that the latest contact was within 12 months. Diminishing the risk of recollection errors was also the reason that the SLPs were asked to report on the latest intervention and not their average experience of intervention to clients with Rett syndrome. They were also asked whether they considered the latest client to be typical for Rett syndrome. However, caution in interpreting the results is called for given that survey data are not supported by observational data or firsthand reports from everyday interaction partners.

The study was limited to investigating SLPs, which is only one of several professional groups involved in aided communication intervention (other groups are occupational therapists and teachers). However, SLPs often have the formal responsibility for assessment, implementation and evaluation of communication aids in the Swedish health service.

Another reason for focusing on SLPs is the low prevalence of Rett syndrome. To gain an overview of communication intervention provided to the group in total it was considered important to reach all members of at least one professional group. A possibility still exists that some SLPs were overlooked in the recruitment procedure. However, from the number of SLPs on the final invitation list, it is safe to conclude that a large majority of the target group was reached. Of the whole group of SLPs targeted, 58% completed the first two parts and thus answered the question whether they had experience of communication intervention targeting at least one person with Rett syndrome. It cannot be ruled out that SLPs with experience of Rett syndrome were among the non-respondents. There is also a risk of bias to the extent that the SLPs who completed the survey might be more engaged or more positive to AAC or in other ways have more positive experiences than those who did not complete the survey. Generalisability might also be hampered because one of the county councils is underrepresented because of a low response rate. However, the structure of the healthcare services for that specific area is the same as in the rest of the country.

To the best of our knowledge, no attempt has been made to overview the intervention provided to people with Rett syndrome. Therefore, despite any methodological limitations, the present results add to the knowledge base of AAC services targeting this specific group.

Conclusions

The main finding was that 87% of the respondents reported that the intervention included communication aids with predominantly estimated positive outcomes, e.g. clarified or increased communicative contributions of the client with Rett syndrome. Communicative functions used to express wants and needs were most frequently targeted. Functions oriented at conversation were not targeted at all by half of the participants. Most SLPs involved everyday interaction partners in assessment and intervention. Responsive partner strategies are well supported to facilitate communicative development and many of the SLPs reported using these strategies as a part of the intervention. The abilities of the individual with Rett syndrome were reported to have developed to a small extent in evaluation of general communication intervention or were unknown. However, there was little use of systematic tools in assessment and evaluation. Instructions to the interaction partners were largely given in informal conversation. Tools and best practice guidelines are needed to support SLPs in the AAC process for this population.

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Declaration of interest

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