Parent and therapist perspectives on "uptime" activities and participation in Rett syndrome

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\textbf{ABSTRACT}

\textbf{Purpose:} People with a disability may spend more time sitting and lying ("downtime") and less time standing and walking ("uptime"). Caregivers and therapists supporting individuals with Rett syndrome were surveyed, aiming to gather insights on how to support participation in "uptime" activities.

\textbf{Method:} An anonymous online survey including openended questions about the enablers and barriers to "uptime" was administered to parent/caregivers and therapists/health professionals in an international sample. Responses were coded to the International Classification of Functioning, Health and Disability (ICF) framework identifying barriers, enablers, and strategies for increasing uptime activities.

\textbf{Results:} Parents (\(N=115\)) and therapists (\(N=49\)) completed the survey. Barriers and enablers to "uptime" were identified for all ICF domains and additional data coded to enabling access to the physical environment. Strategies to promote "uptime" activities and participation particularly related to the individual's physical capacity and personal factors as well as social and physical environmental factors.

\textbf{Conclusions:} Findings can inform the design of interventions aiming to increase "uptime" in individuals with Rett syndrome. Strategies should create individualised support by considering how to build fitness using activities that are motivating, at the same time creating opportunities for social interactions within a range of environments.

\section*{IMPLICATIONS FOR REHABILITATION}

- "Uptime" participation comprised a dynamic interaction of "doing" the standing or walking activity, with a sense of self-engagement with the activities and interaction with others.
- Strategies to promote "uptime" participation should consider how to create support for person-related attributes, including building physical capacity for a greater volume of "uptime" in activities that are enjoyable and motivating.
- Strategies to promote "uptime participation should also include creating a supportive environment, comprising opportunities for social interaction within a range of environments".

\section*{Introduction}

Rett syndrome (RTT) is a rare genetic disorder, mostly affecting females with a birth prevalence of 1:9000 live female births [1]. After seemingly typical development, symptoms of regression of speech and loss of hand function usually become apparent between six to 18 months along with the development of hand stereotypes and gait abnormalities [2]. Common co-morbidities include epilepsy, scoliosis and sleep problems [2]. The degree and speed of regression varies widely [3] and there is a diversity of functional abilities within the RTT population, partially attributed to genotype [4–6].

The health benefits of being physically active have been well established in both the typically developing population [7] as well as in populations with disabilities [8]. It is important to ensure support for access to opportunities for and engagement with physical activities for all individuals in the population. In RTT, the ability to walk independently or with assistance is associated with health outcomes including reduced incidence of lower respiratory tract infections [9] and less rapid progression of scoliosis [10]. Motor impairments and dependence on others for activities challenge the capacity of individuals with RTT to lead physically active lives compared to their typically developing peers [11,12]. As such, individuals with RTT face barriers to being physically active, particularly due to their need for assistance and support for activities from caregivers, support workers and therapists [13].

As would be expected, physical activity involving standing and walking (collectively, termed “uptime” [14]) is reduced in RTT [12,15]. Reduced gross motor function is in turn associated with reduced participation for those with RTT [16]. Participation can be defined according to the International Classification of Functioning, Disability and Health (ICF) as “meaningful involvement in a life situation” [17]. Lack of participation in meaningful activities across home and community settings may then be
associated with reduced quality of life [16]. Thus, there is the possibility that interventions aiming to increase “uptime” activities, with strategies including standing and walking activities that are meaningful in home and community settings, could have a positive impact on physical activity and indicators of wellbeing including quality of life [18]. For example, immersion in the community and participation in a variety of activities were found to be important domains of quality of life scores in children with RTT [19] and the frequency of participation predicted quality of life, independently from the level of functional abilities, in children with intellectual disability including RTT [16].

Important components of meaningful engagement with activities include being actively involved, feeling included when engaging socially with others, making choices and enjoying the activities [20]. Motivation [21] and choice-making [22] have also been shown to be important aspects of engagement in RTT. How these components are implemented may depend on attributes of the child such as levels of functioning and preferences, attributes of the family and other caregivers such as socioeconomic status and availability of time, and attributes of the human and physical environments such as attitudes, supports and services, each of which can support or challenge the child’s meaningful engagement with activities [20]. These components were previously identified in a qualitative evaluation of the facilitators and barriers to “uptime” in RTT: personal preferences intersected with the physical, social, organizational, and attitudinal environments [13]. Incorporating these components for optimal participation into an intervention to increase “uptime” in RTT could enhance meaning and effectiveness of the “uptime” strategies.

ActivRett is a randomized, controlled wait-list clinical trial that proposes to deliver physiotherapy support via telehealth to support families of individuals with RTT to increase the quantity of “uptime” within a participation framework and potentially also quality of life (NCT04167059) [18]. A formative task for this trial was to first seek the perspectives of those in the community who support activities in individuals with RTT, to inform the breadth of possible strategies that promote “uptime” that are relevant to this group. Using an online survey of parents and therapists/health professionals, we aimed to understand how families and therapists promote optimal use of “uptime” in RTT. This involved (1) classifying barriers and enablers for increasing “uptime” within the ICF framework, and (2) describing strategies for increasing “uptime” using the F-words analogy for the ICF framework, including the terms fitness, function, fun, friends and family [23].

Materials and methods

Study design

Two surveys were developed, one for parents/caregivers and another for therapists/health professionals. All data were collected between May and September 2019. A generic link to the survey which was available in five languages (English, Danish, Dutch, French and Hebrew) was provided. Respondents were anonymous and online consent was collected at the end of the information sheet. Ethics approval was obtained from the University of Western Australia (RA/4/20/5386).

Participants

Participants were parents, caregivers, therapists or other health professionals internationally who are involved or were involved in the past in the care or support of at least one individual with RTT. One hundred and fifteen parent/caregivers from 28 countries provided responses to the parent survey. The majority were the biological parent with the individual with RTT living in the parental home, and more than half completed the survey in English. Forty-nine therapists/health professionals from four countries (Denmark, the Netherlands, Australia, Israel) provided responses to the therapist survey, the largest proportions from the Netherlands, Denmark, and Australia. They reported variable experience with RTT and two thirds were physiotherapists. Participant characteristics are presented in Table 1.

Survey content

The parent/caregiver and the therapist/health professional surveys were designed by the investigator team based on findings from previous research [13] and are presented in Supplementary Appendices 1 and 2. Demographic questions describing the participants and the individual with RTT who they cared for or supported had defined response categories, and these were followed by open-ended questions about specific “uptime” activities that the individual with RTT enjoyed at home, school, and in the community, and what (if anything) was difficult or frustrating during these activities. We asked for recommendations of how “uptime” could be enjoyable and successfully supported and what resources should be available to support planning of “uptime” routines. The therapist/health professional survey also asked what equipment was helpful in achieving “uptime.” Both surveys were designed in English and using available resources, were translated by native speakers into Hebrew, Dutch, Danish and French, who were also fluent in English, to enable responses from the broader RTT community.

Survey administration and distribution

The questionnaire was administered online using the secure web application, Research Electronic Data Capture (REDCap™), a web-based secure application to collect clinical data for research [24]. We identified recruitment avenues and networks to reach potential participants, including advertising the study and the generic survey link with the social media platforms of advocacy organisations for Rett syndrome with whom we have previously worked. These included the Australian Rett Syndrome Association, Rettsyndrome.org (USA), Rett Syndrome Europe, the Rett Syndrome Association Netherlands and the Danish and Israeli Rett Syndrome Parent Associations who disseminated the information using Facebook. The investigators also emailed the generic survey link throughout their own clinical and professional networks. Potential participants were advised that the survey would take approximately 10 min of their time. One reminder was sent through the advocacy organisations and the investigator networks. Responses were collected over a six-week period from May to July 2019. Of the survey questions which provided data for the analysis, 14 of 460 (0.03%) parent fields and 12 of 245 (0.05%) therapist fields were missing.

Data analysis

First, all responses were translated to English by individuals fluent in the English language, whose first language was the relevant questionnaire. Parent/caregiver and therapist/health professional data were coded together. Data were reviewed to identify patterns of ideas and phrases across the interviews. Directed content analysis methods [25] were used to code similar responses into the main domains of the ICF [17], that is to the domains of

"UPTIME" IN RETT SYNDROME
Impairment, Activity, Participation, Environmental Factors or Personal Factors. Within each ICF domain, data were coded as subdomains of opportunities, barriers and enablers to “uptime.” Data describing strategies to support “uptime” were extracted and tabulated. Coding was performed using NVivo software [26] and discussed and checked by three investigators (NB, MS, JD).

Results
Description of the barriers and enablers to “uptime” in each of the ICF domains, that each influenced and determined opportunities for standing and walking, is first presented below. Strategies are then described and presented in Figure 1.

Aim 1 - Barriers, and enablers within each ICF domain

Body functions and structures
Impairments relating to physical and mental health as well as limitations in functional abilities were mostly reported as barriers to “uptime” activities. Musculoskeletal comorbidities were frequently reported including altered muscle tone, muscle stiffness and joint contractures including scoliosis, muscle weakness and difficulties maintaining upright positions, poor balance and difficulties with motor planning including dyspraxia. These occur commonly in Rett syndrome and may be considered to indicate need for physical activities.

She is vulnerable on her feet and easily gets knocked over or falls over.
– Parent

Difficulties in balance that make her anxious and so her breathing becomes irregular.
– Therapist

Comorbidities such as seizures, autonomic breathing patterns, constipation and bone fracture each imposed additional barriers to “uptime.” Mental health was also an influencing factor, reported as low mood or anxiety.

After a broken leg, progression of flexion contractures and scoliosis, and the loss of muscle strength reduced her [capacity] for “uptime.”
– Parent

[When] breath-holding and absence seizures increased – in these moments the child couldn’t maintain an upright position and therefore was at risk of injury ….
– Therapist

Table 1. Descriptive data of parent/caregiver and therapist/health professional respondents.

| Parent caregiver respondents (n = 115) | N (%) |
|---------------------------------------|-------|
| Country of residence                  |       |
| Armenia, Australia, Austria, Belarus, Brazil, Canada, Finland, Georgia, Greece, Hungary, Italy, Macedonia, Netherlands, Serbia, Spain, Sweden, Switzerland, United Kingdom, United States | 67 (58.3) |
| Denmark                               | 20 (17.4) |
| Israel                                | 15 (13) |
| Belgium, The Netherlands, Slovakia     | 7 (6.1) |
| France, Sweden, Switzerland, Tunisia  | 6 (5.2) |
| Area of residence                     |       |
| Large city                            | 33 (28.7) |
| Small city                            | 57 (49.6) |
| Rural setting                         | 25 (21.7) |
| Type of residence                     |       |
| Parental home                         | 98 (85.2) |
| Group home                            | 14 (12.2) |
| Independent living                    | 3 (2.6) |
| Relationship of respondent to the child with Rett syndrome |       |
| Biological parent                     | 110 (95.7) |
| Grandparent                           | 1 (0.9) |
| Foster parent                         | 1 (0.9) |
| Sibling                               | 3 (2.6) |

| Median (range) |       |
|----------------|-------|
| Age of child with Rett syndrome (years) | 13 (2 – 54) |

| Therapist and other caregiver respondents (n = 49) |       |
| Country of residence                              |       |
| Australia                                         | 11 (22.4) |
| French speaking country                           | 1 (2) |
| The Netherlands                                    | 17 (34.7) |
| Denmark                                           | 16 (32.7) |
| Israel                                            | 4 (8.2) |
| Area of residence                                 |       |
| Large city                                        | 25 (51) |
| Small city                                        | 19 (38.8) |
| Rural setting                                      | 5 (10.2) |
| Profession                                        |       |
| Physiotherapist                                    | 34 (69.4) |
| Occupational therapist                            | 2 (4.1) |
| Support worker                                     | 8 (16.3) |
| Other (teacher, relaxation therapist)              | 5 (10.2) |

| Median (range) |       |
|----------------|-------|
| Years since receiving qualification               | 15 (1 – 42) |
| Number of individuals with Rett syndrome that therapist has worked with | 2 (0–120) |
| Number of individuals with Rett syndrome currently working with | 1 (0–65) |

aCompleted survey in English. bCompleted survey in Dutch. cCompleted survey in French. dNot reported.
For some individuals, these impairments fluctuated with episodes of illness. Even when well, fatigue was frequently described and many individuals were observed to be in pain, described as due to gastrointestinal dysfunction or joint pain.

Fatigue can be physically heavy for the caregiver – success is varying; one day, she will take weight on her legs, the next day she will sag. – Therapist

So obviously, exhaustion and pain have an enormous effect on her mood. – Parent

Enablers that countered the detrimental effects of impairments on “uptime” included use of a support person or equipment to help body alignment and balance as well as support to initiate movement and overcome the effect of dyspraxia and to maintain the pace of walking, illustrating interconnectedness between the ICF domains. Meaningful eye contact or “eye pointing” was commonly noted in many of the responses, particularly when “uptime” activities provided opportunity for being on eye level with friends and family.

She gets help to initiate walking, [she] has no initiation to start walking. – Therapist

She needs to have the energy; you can trigger it by getting things rolling with music and eye contact. – Parent

Activities

Data in this ICF domain described a range of standing and walking activities and exercise regimens. Standing and walking activities were described with or without support, during activities at home or therapy sessions. Other activities included swimming, horse riding, climbing, and dancing. Barriers to performing these activities usually related to the level of motor abilities, with “uptime” activities more easily implemented for those able to perform skills such as standing, walking, or even running and climbing independently. Providing supports or adjusting the duration of activities to suit fitness were reported as compensating enablers.

Holding her hand or arm works well though someone has to be fit and strong to take her weight and lower her carefully to the ground when she has a seizure. – Parent

She likes walking and standing in itself, the change of positions, rising up for the activities that accompany it, singing songs while walking and doing something while standing. – Therapist

The activity of making choices and having control over activities was frequently described.

She can get sad when she doesn’t feel like walking anymore. Then we return immediately and tell her we are going home just as she showed us. – Parent

It is important to ask them, they can let you know what they want through a communication aid. – Therapist

Participation

Participation was described in home, school or day centre and community settings. In the home setting, common activities occurred in the kitchen and often involved participating in chores, sometimes watching and other times actively helping to make snacks, helping with the dishes, or setting the table for a meal. Additionally, “uptime” activities were used for eating, personal care, play and educational activities such as reading, using eye gaze communication devices, watching television, using a trampoline and for social interactions with families and friends. Outside home activities included picking up the mail from the mailbox or exploring the garden or farm.

Hand over hand, assorted cooking activities, standing at the supper table to make sure she is part of the conversation. – Parent

Walks around the farm … walking up the small rock formations on the farm, walking to see the animals … to choose where she wants to be and choosing to sit in various chairs around the yard. – Parent

“Uptime” activities were similar in school or day centre settings with new opportunities being available. For example, “uptime” could be associated with specific learning activities such as sport or music, helping with school duties, participation in events including and opportunities to explore surroundings both indoors and outdoors.

For example, standing enabled contact/communication with her classmates and teachers, being part of a group of other children who are also in a standing frame. – Therapist

They take her to the kitchen walking …. She helps in reporting who is absent from the centre. – Parent

At a joined activity across the whole day centre, the woman could walk around on her own …. she could greet many people, and this led to lots of smiles during the activity. – Therapist

Other “uptime” activities were reported in community settings such as swimming, going shopping or to the park, horse-back riding, and visiting museums or the zoo. Social experiences and activities in nature and the outdoors were commonly described.

We take an all-terrain wheelchair to go out and about … spending time on foot …. using the chair for resting. – Parent

in the woods with hills, stones on the ground, waterfalls in the neighbourhood; she loves difficult situations, loves to see bicyclists and dogs passing …. – Parent

Barriers and enablers of uptime participation related to the body functions and structures domain and the environmental and personal factors of the ICF (described below).

Environmental factors

Barriers to “uptime” in the environment included lack of aids and equipment or physical support, to provide assistance for balance or if endurance was poor; having poor fitting orthotics; lack of staff to support “uptime”; limitations in the knowledge and attitudes of helpers; parents having physical and emotional resources to support “uptime”; characteristics in the physical environment including barriers of noise, stairs or challenging terrains; and uncomfortable weather.

In the perfect world, we would have unlimited energy and enthusiasm for keeping her entertained and engaged. In reality, we are old and both physically and emotionally exhausted. – Parent

[Uptime is difficult] when she is too hot or the road is icy. Also when she is cold, she can’t move herself around well. We have to help her putting one foot after the other while guiding her hands, her body and legs, until she can do it herself. – Parent

To counterbalance, each of these factors in the environment could contribute to enjoyable “uptime” participation when structured differently: if resources were available; caregivers had suitable knowledge, understanding and available time; the outdoors environment was utilized; and the benefits of feeling comfortable with routines activities were appreciated. Collaborations between caregivers and between settings could help to achieve the individual’s “uptime” goals. Many comments described the capacity of the environment to enable enjoyable “uptime.”

At one point, the day centre could not help her use her walking device ... with a Rett centre effort between the day centre and the Rett centre, she can now use her walking device again. – Parent
Going to a familiar garden centre where they have tropical fish, various birds and insects with a café that she knows well. It is successful because it is familiar, and she knows the layout.” – Parent

**Personal factors**

Personal factors that acted as barriers to “uptime” related to the preferences of the individual and their capacity for self-determination. Examples included the individual being bored or disliking the activity; the activity being without meaning or a goal; or when the individual felt misunderstood. Other personal factors included when effort was disturbed by distractions or others, or due to fatigue and exhaustion.

When siblings join the ongoing activity and require attention or are too noisy. It is best with one-on-one focus. – Parent

Unexplained tears because we don’t understand what she wants. – Therapist

On the other hand, “uptime” activities that were associated with meaningful goals, feeling competent, having choice and control to participate in activities that are enjoyable and motivating, each enabled greater enjoyment and happiness. Having trust in caregivers was described as important for the individual to feel safe and secure.

Being in the same position as her peers – eye level. – Therapist

when she has people around her who can understand her, who gives her what she needs in her everyday life. Then she becomes happy, cheerful, and very glamorous. It will be a fine interaction. – Parent

**Aim 2 – Strategies to promote “uptime” (Figure 1)**

Strategies to promote “uptime” activities and participation particularly related to the individual's physical capacity and personal factors as well as social and physical environmental factors. Strategies were therefore coded into two main themes “Creating support for person-related attributes” and “Creating a supportive environment,” and thereafter further classified into subthemes that were consistent with the F-words framework: “Fitness and Function – Evaluate and build capacity for ‘uptime,’” “Fun – Find strategies that support mental health and motivation,” “Family and Friendships – Build a rich social environment” (Figure 1). Other data coded to a new sub-theme of the “[Fysisk]Physical environment – Enable access to opportunities,” a new “F”-word that referred to strategies relevant to the physical surroundings and settings in which “uptime” is supported when identified strategies.

The “Fitness and Function” subtheme was consistent with the body functions and structure and activities domains of the ICF. Strategies related to building endurance and fitness into everyday functional tasks and overcoming difficulties, e.g., in areas of motor planning and dyspraxia.

Try to shoot for the “sweet spot” in the day after a nap or a meal, when the individual is primed for success and enjoyable experience” – Parent

Game of hide & seek with siblings and neighbours. Usually, they would run inside and out of a double-storey house and hide in places not accessible to her. Ground rules were changed to make it work. Limited to upstairs of the house only and she was the seeker – Parent

“Fun” involved the ICF domains of personal factors and participation. Here strategies included ensuring high levels of motivation, engagement and enjoyment by providing participation in “uptime” activities that are meaningful, social, self-determined and provide a sense of competence.

Find out what they enjoy and engages them and weave this into the uptime activity sessions. Use music, such as singing special favourite songs or other means to get them motivated and to provide an association with what is going to happen – Parent

Most activities are successful when you use praise, happy voices and cheering – Parent

She should experience that she has something to offer to the community and her peers with the qualities and skills that she has – Therapist

We always give her the choice of what she wants to do and support her when needed – Parent

The social environment was expressed in the subtheme “Family and Friends” and linked to the environmental factors (Figure 1).

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**Figure 1.** Summary of strategies to support “uptime” activities and participation in Rett syndrome.
and participation domains in the ICF. This subtheme underlined the pivotal role that family, friends, teachers, support workers and therapists play in the lives of those affected by RTT. Strategies encouraged different members in the social environment to be persistent and collaborate.

We help her stand to participate in activities (play etc) with her friends from the neighborhood or with other kids – Parent

These examples [activities] are successful because they are social activities with interactions with one or two parents, siblings or other children – Parent

Additionally, the “[Fysisk]Physical environment” subtheme was created and considered important as external conditions can greatly influence the individual’s opportunities to engage in “uptime” activities. Adaptive equipment that support standing and walking is highly recommended. The indoor and outdoor settings should be accessible and flexible to fit the changing needs of the individual.

Allow your child to work out and follow their own circuit around the environment. Help them with their motor planning initially but allow them to try and work it out. Equipment really helps – Parent

We made some adjustment in the house - we used two long shelves on the wall to hang different toys from. They were placed in a position that required her to stand. She would then move around for hours in her walking device and push buttons, balls and activate sounds and lights – Parent

Earlier we had success when we placed a lot of chairs along the way. She should then pick up something from the chair and then she could sit down for a break – Parent

Discussion

The present investigation was focused on collecting the perspectives of parents and therapists to provide an understanding of how “uptime” is experienced by individuals with RTT. The ICF framework [17] informed and enabled classification of these experiences as well as what helps or hinders experiences of “uptime” activities. We then classified strategies for supporting “uptime,” also within the ICF framework but described using the F-words [23]. Each of the F-words or ICF domains were represented but we identified a further domain describing the [Fysisk] Physical Environment that grouped an additional set of strategies relevant to the planning and implementing of “uptime” strategies.

RTT causes movement limitations, often coupled with multiple comorbidities [2], thereby creating a high level of dependency on the social and physical environments for addressing daily needs [27]. Given these support needs, it is not surprising that there is also a high risk that physical activities such as standing and walking are reduced [12,15] and sedentary time is elevated [11,15]. However, despite these complexities, there is great capacity for individuals with RTT to engage in “uptime” activities and participation with planning and support. Using qualitative methodology, we have previously reported that the balance of enablers and barriers influenced how “uptime” activities were planned and implemented [13]. Data in the current study has provided further insights.

Respondent observations identified multiple aspects of Body Structure and Function that were barriers to “uptime” activities and participation, particularly musculoskeletal impairments and dyspraxia and further complicated by physical health comorbidities [2] and sometimes difficulties with mental health and behaviours [28]. Meaningful eye contact or “eye pointing” is a strength in RTT [29,30] and was commonly noted in many of the responses as enabling choices and enjoyment to be expressed. Also within this ICF domain, enjoyment of routines and movement were reported as enablers for “uptime,” consistent with domains of quality of life that have been identified as important for individuals with RTT [19,31].

A wide range of “uptime” activities were described, including standing and walking exercise regimens that were built into home, school or activity/day centre routines. However, “uptime” activities were more frequently described within the Participation domain, and were also built into home, school or activity/day centre settings but also into a broader range of community options. For the Activities and Participation domains, barriers referred to functional impairments, comorbidities as well as additional social and physical factors in the environment. Previous research has also shown that it’s important to enhance the ability of choice-making for motivation in individuals with RTT as they are capable of making choices which can improve the overall quality of life [21,22]. Putting emphasis on collaboration, social interactions as well as the individual’s personal needs and wants, preferences and self-determination enhanced motivation and enabled participation. In educational settings, previous research has also shown that it’s possible to increase motivation and attention in individuals with RTT which provides important learning opportunities [21]. The identified barriers and enablers are consistent with the model of optimal participation [20], where our data described the dimensions of participation: “uptime” participation comprised a dynamic interaction of the (1) physical “doing” of the “uptime” activity, (2) social engagement and interaction with others, and (3) a sense of self-engagement where the individual has the energy and desire to participate in the preferred activities.

We elected to code strategies to the F-words operationalization of the ICF framework [23], to link strategies more closely with how people live and how optimal participation and living can be supported practically. Each of the F-words (ICF domains) were represented but strategies coded to Fitness (Body Structure and Function) and Function (Activities) in combination, and to Friends (Participation) and Family (Environmental Factors) in combination. These combinations illustrated the interconnectedness of domains that need to be considered when planning supports for persons with a disability and how the F-words framework allows conceptual and contextual descriptions of comprehensive and strengths-based supports to living well [32]. As such our derived strategies mapped to the richness of the ICF model and combined the important concepts of choice, preferences and building opportunities for fitness into meaningful social environments.

We identified a further domain of strategies to support “uptime” that described the [Fysisk]Physical Environment. Whilst not defined as an F-word [23], the [Fysisk]Physical Environment refers to physical aspects of the natural and built environment which are also recognized as part of the ICF [17]. Inadequate or inaccessible facilities, uneven or inappropriate surfaces, and lack of adaptive equipment in the physical environment have been described as barriers to physical activity among children and adults with physical and/or intellectual disabilities [33–36]. However, the physical environment has been reported to be critical in finding the right balance for physical activity participation in both children and adults with childhood-onset physical disabilities [36]. Our respondents reported that promoting “uptime” in RTT involved considering the congeniality of the environment, whether activities could be possible across indoor and outdoor settings, and recognized that adaptations in terms of adaptive equipment and adjustments to furniture were often needed. Given the large impact the physical environment has on participation opportunities our data again support calls for available and accessible
designs in public spaces to ensure the rights of persons with a dis-
ability for equal inclusion in the community and involvement in
-cultural life [37]. It is important that clinicians support families in
finding useful equipment, strategies to overcome barriers and
advocating for better accessibility. Partnerships with policy-makers
can work towards creating more inclusive communities [34].

**Strengths and limitations**

We used a social media-based survey distribution strategy sup-
ported by multiple advocacy organisation groups for RTT, ena-
bling international scope and including the perspectives of
respondents from 28 countries and across four continents, repre-
senting a variety of geographical and cultural settings. This di-
versity of perspective was further enhanced by the inclusion of both
parent/caregiver and therapist/health professional experiences.
We were however unable to estimate a response fraction since
we do not know how many individuals were notified of the sur-
vey but chose not to respond. We also acknowledge that most
participants lived in the developed world, and that although not
necessarily representative, small numbers lived in rural settings.
We elected not to collect detailed clinical data about the individu-
als with RTT which would inform the determinants of “uptime,”
because our aim was to generate practical information pertaining
to how “uptime” activities are implemented. Our online survey
collected short answer responses to questions rather than in-
depth responses on “uptime” and whilst many responses were
brief, we were gratified that many participants provided detailed
descriptions that clearly illustrated their experiences. There is the
small possibility that two parent/caregivers for the one child with
RTT could have completed the survey. We believe that this would
be an unlikely scenario, but this would not necessarily be prob-
lematic because each parent/caregiver would bring their own per-
spective to the qualitative dataset.

**Conclusion**

Consistent with the ICF [17] and optimal participation [20] models,
our findings suggest that multiple factors pertinent to the person
with RTT and the environment can influence how and how often
“uptime” activities occur. Strategies should include supports that
are person-centred for how to build fitness using activities that
are enjoyable and motivating. At the same time, person-centred
strategies should be intertwined with opportunities for social
interactions within a range of indoor, outdoor, home and commu-
nity environments. As such, parents/caregivers and therapists/
health professionals need to consider these factors in combina-
tion to plan and provide “uptime” activities for individuals with RTT. It
is possible that physical activities, including opportunities for
“uptime” have potential to provide support for current health[9]
and quality of life [16], and could represent important strategies
paying forward for optimal health, wellbeing and quality of life
into the future.

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