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"They think I'm really cool and nice": The impact of Internet support on the social networks and loneliness of young people with disabilities

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Abstract

Today, young people use the Internet for social networking, learning and recreation. Young people with disabilities have fewer friends and reduced social networks. The aim was to investigate the effectiveness of one-on-one training to increase the use of the Internet by young people with disabilities to enhance their social networks and reduce loneliness. Eighteen young people aged 10-18 years with cerebral palsy, physical disability or acquired brain injury completed a social networks inventory and level of loneliness measure. Participants received assistive technology and training at their home to learn to use the Internet for building social networks. Post intervention testing revealed that the number of online communication partners increased significantly; however, there was no difference in measured levels of loneliness. Future research with larger number of participants with disabilities needs to be followed up longitudinally including investigating the meaning and role of online social connections for this group

Introduction

Adolescence, a time for significant change physically and emotionally, is also when peer relations and identity become important. Recent research with adolescents highlights that relationships with friends are important for their overall health and well-being and social adjustment (Corsano et al. 2006^[9]; Waldrip et al. 2008^[10]). In a survey by Helseth & Misvaer (2010^[11]) adolescents emphasised the importance of peer relations to promote and sustain their quality of life.

Connectedness with friends has been recognised as an important aspect of life participation for young adults with disabilities Newman et al. 2011^[12]). Studies have shown that young people with cerebral palsy and other disabilities worry about making friends and have smaller social networks (McMaugh & Debus 1999^[13]; Raghavendra et al. 2011a^[14]; Thirumanickam et al. 2011^[15]). They have also been shown to have fewer reciprocated friendships and are more isolated than their peers without disability (Nadeau & Tessier 2006^[16]). Young people with disabilities with and without complex communication needs tend to have fewer friends and acquaintances compared to their typically developing peers (Raghavendra et al. 2012a^[17]), and those who use augmentative and alternative communication may be at higher risk of loneliness due to limited communication abilities (Cooper et al. 2009^[18]). This can be due to many personal and environmental factors including increased reliance on family and paid caregivers to access social situations resulting in limited opportunities for young people with disabilities to develop friendships (Blum et al. 1991^[19]). In a recent qualitative study examining transition issues for young people with disabilities, parents recognised significant challenges in helping their children with disabilities connect with others and identified supporting the development of social networks as a key priority (Rhem 2012^[20]). Previous research in adults with acquired disability has identified reduced social networks following injury as a concerning indicator of increased social isolation (Vickers 2010^[21]).

Some of the challenges in making and maintaining friends and strengthening social interaction for children and adolescents with physical and/or multiple disabilities, could potentially be overcome through Internet social networking. The Internet could provide an opportunity for asynchronous communication without prejudice and time pressure (Barnfather et al. 2011^[22]; Lewis 2010^[23]; Raghavendra et al. 2012b^[24]). The young adults with disabilities in Cooper et al.'s study (2009^[18]) highlighted the importance of Internet technologies in developing friendships and reducing feelings of loneliness.

Internet use in young people with disabilities is an under researched area. The authors have conducted a pilot study via postal and phone surveys and interviews on Internet use patterns, enablers and barriers in 10-18 year olds with cerebral palsy (CP), muscular dystrophy (MD) and acquired brain injury (ABI) (Newman et al. 2010^[12]; Raghavendra et al. 2011b^[25]; Raghavendra et al. 2012b^[24]). Results showed that 95% of participants used the Internet, for purposes such as instant messaging, emailing, homework, using YouTube, and social networking with existing friends and family. The main factors enabling use were support from siblings and friends. The main barriers were family-level computer/Internet literacy and resources, and some disability-related factors (Raghavendra et al. 2012b^[24]).

A UK study asked 14 young adults with CP above 18 years of age about their experiences and challenges in using online social networking (Lewis 2010^[23]). The findings showed that the participants used primarily Facebook, for up to six hours a day at home, place of work or educational settings. They communicated predominantly with their family members and friends who were also the ones that introduced them to online social networking. The benefits of online social networking were: independent and private communication, and reduced isolation. The challenges related to sudden changes in the setup of online social working sites and technical difficulties with equipment. In spite of this, participants' responses indicated that they considered online social networking as a vital way to communicate.

One Australian online site for youth with chronic illness or disabilities (www.livewire.org.au^[26]) found that members extensively used the moderated chat forum and formed new friendships online. The site was also deemed socially safe with a high level of peer support (Collin et al. 2011^[27]). A 6-month online intervention study in Canada used five trained peer supporters for 22 adolescents with CP or spinal bifida (SB) who felt that the support helped to learn new information, to meet others with disability, and to make new friends (Barnfather et al. 2011^[22]; Stewart 2011^[28]).

However, there is little if any research that has investigated the effectiveness of individualised training and support provided to young people with disabilities with the aim of increasing their Internet use for social networking purposes. A larger study by the authors investigated the objective and subjective outcomes of interventions to support using Internet social networking for increasing social participation Raghavendra et al. (in press^[29]). The aims addressed in this paper are:

1. What is the effectiveness of interventions (i.e. providing appropriate technological solutions, training and support) in increasing the use of Internet social networking of young people with disabilities on their online and offline social networks?
2. What is the effectiveness of above interventions to increase the use of Internet social networking of young people with disabilities on their loneliness?

Method

Ethics approval was obtained from the Children, Youth and Women's Health Services Human Research Ethics Committee. The methodology as reported by Raghavendra et al. (in press^[29]) is outlined in this section.

Design

The authors conducted a larger study using a sequential fixed mixed-methods design Klassen et al. 2012^[30]). The intervention's effectiveness was measured using a pre/post group design where each young person was their own control (Schlosser 2003^[31]). Since each young person had individualised goals and tailored training and support strategies, this design was considered the most appropriate. The young person and their parents were interviewed after the intervention. The outcome of the interviews is included in Raghavendra et al. (in press^[29]) and Grace et al. (2012^[32]). However, comments from the participants relevant to the current aim will be included.

Participants

Participants were young people aged 10-18 years with physical disabilities such as CP, MD or other physical conditions, or ABI, and with and without complex communication needs, living in metropolitan Adelaide, South Australia. Those who were at pre-intentional level of communication were excluded from the study. The young person, parent or a professional could indicate the need for the young person to learn to use, or increase their use of, the Internet for social networking. Families needed to have a computer and Internet access at home.

The inclusion criteria were advertised to staff at Novita Children's Services, an organisation providing services to children with physical disabilities from birth to age 18 in the state of South Australia, and in the client newsletter. Staff or parents nominated 123 eligible clients of Novita and invitations to participate were sent to them. Twenty-two consented, but four subsequently withdrew, leaving 18 participating (15% of 123 invited). The demographic information of the young people is presented in Table 1. The mean age was 13.7 years; 66.7% were boys, had cerebral palsy or other physical disabilities, attended high school (from Grade 8 and above) and were in special units within mainstream schools.

The young person's gross motor and hand function was classified based on the Gross Motor Function Classification System (GMFCS, Palisano et al. 2008^[33]) and the Manual Ability Classification System (MACS, Eliasson et al. 2006^[34]). Communication ability was classified using the new Communication Function Classification System (CFCS, Hidecker et al. 2011^[35]) for everyday communication. There are five levels of performance according to the effectiveness of sending and receiving messages with familiar and unfamiliar communication partners. A majority of participants were at Level I of GMFCS, MACS and CFCS, showing that they had minimal physical disabilities and good communication abilities. However, five with complex communication needs had mild to severe physical disabilities (Level I, IV and V of GMFCS and MACS, and Level III and V on CFCS). Those on Level V on GMFCS and MACS were participants with severe limitations in head, trunk and hand control, requiring extensive assistive technology and total assistance; mobility was only through powered wheelchair. Young people on Level III of the CFCS were effective senders and receivers with familiar partners, where as those on Level V were seldom effective senders and receivers with familiar partners (Hidecker et al. 2011^[35]). Even though 78% were on Level I to III on GMFCS, the 22% on Level IV and V had complex communication needs.

	N	%	Diagnosis	N	%
Gender					
Male	12	66.7%	ABI	5	27.8%
Female	6	33.3%	CP	6	33.3%
			Other PD	7	38.9%

Age (Mean, SD) 13;7 (2;3)

	N	%		N	%
*GMFCS level			**MACS level		
I	11	61.1%	I	9	50.0%
II	1	5.6%	II	5	27.8%
III	2	11.1%	III	2	11.1%
IV	3	16.6%	IV	1	5.6%
V	1	5.6%	V	1	5.6%

	N	%		N	%
***CFCS level			Complex Communication Needs	5	27.8%
I	12	66.7%			
II	0	0.0%			
III	4	22.2%			
IV	1	5.6%			
V	1	5.6%			

School level		Class Type			
Primary School	6	33.3%	Mainstream	7	38.9%
High School	12	66.7%	Special Class	11	61.1%

Table 1 - Demographic information of young people with disabilities.

*Gross Motor Functional Classification System (Palisano et al. 2008^[33])

**Manual Ability Classification System (Eliasson et al. 2006^[34])

***Communication Function Classification System (Hidecker et al. 2011^[35])

Instruments

Social Networks

Social networks can be defined as the framework including all of an individual's social contacts Gottlieb 1981^[36]. Information on social networks was gathered using 'Social Networks: A communication inventory for individuals with complex communication needs and their communication partners', developed by Blackstone & Hunt Berg (2003^[37]). This inventory gathers information on communication abilities and about an individual's Circle of Communication Partners (CCPs). This is a visual representation of the individual's social network to identify partners in each circle:

- Circle 1 lifelong communication partners such as family and close relatives
- Circle 2 good friends
- Circle 3 acquaintances such as classmates and neighbours
- Circle 4 paid workers such as teachers, doctors and specialists
- Circle 5 includes unfamiliar partners (e.g., shopkeepers)

The CCPs has been used in previous research as a suitable tool for describing social networks of individuals with disabilities Raghavendra et al. 2012a^[17]; Vickers 2010^[21].

Each young person was shown a diagram of the Circle of Communication Partners. Each circle was explained and examples were provided. The participants were then asked to list all the people they knew and interacted with in each circle. For this study a new Circle 6 was added, focusing on online communication partners, those the participants communicated with either via Facebook, Skype, email and/or online games. The information about online and offline communication partners was gathered before and after intervention.

Loneliness and Social Dissatisfaction Questionnaire for Children (LSDQC)

The participants' feelings of loneliness were assessed using the Loneliness and Social Dissatisfaction Questionnaire for Children Asher et al. 1984^[38]. This self-report measure consists of 16 primary items that focus on feelings of loneliness and social dissatisfaction at school (e.g., "I am lonely at school," "I have nobody to talk to in class") and eight filler items that focus on hobbies and interests ("I watch TV a lot", "I like music"). Children indicated how true each item was for them on a scale from 1 (Always true), 2 (True most of the time), 3 (Sometimes True), 4 (Hardly ever true) to 5 (Not true at all). For selected items, the scoring order is reversed. When responses to the 16 primary items are summed up, scores can range from a low of 16 to a high of 80, with higher scores indicating greater feelings of loneliness. The scale has a good reliability (Asher et al. 1984^[38]). The tool has been used to examine changes in loneliness following online peer support for young people with physical disabilities (Stewart et al. 2011^[28]).

Procedure

The research officer administered the Canadian Occupational Performance Measure (COPM, Law et al. 1998^[39]), to each young person and their parent together. This identified problems in Internet use, focused particularly around building social networks and social participation. The Circle of Communication Partners responses were noted by asking the participant and/or the parent to list the names of people that the participant communicated with in each circle. The research officer asked prompt questions where necessary to help the young person and their parent to think of and remember various communication partners in the different circles.

For example, "Do you have any uncles, aunts, or cousins? Do you play any sport, music or have hobbies?" If they said Yes, then they were asked who are the people you interact with and when you do those activities. The five participants who used augmentative and alternative communication used their systems to list names of friends and family. Partner-assisted scanning or "Yes/No" questions were also used. The young person's response was circled on the five-point rating scale of the Loneliness and Social Dissatisfaction Questionnaire for Children. Participants were trained in each rating scale prior to use and supported to provide a nonverbal response. The research officer read each item and the five possible responses on the rating scale.

Goals were also developed for between three and five problem areas using the Goal Attainment Scaling (GAS, Kiresuk et al 1968^[40]). Examples of goals were:

1. To play games online with others;
2. Arrange to catch up with friends and keep in touch via the Internet;
3. To talk with friends (Circle 2 and 3) online from home;
4. To connect with new people on Livewire.

The intervention consisted of the use of appropriate technologies to overcome perceived problems in Internet access/use, and support and training to use the Internet for the specified goals. The intervention was provided to the young person and/or their parents at their home. It also:

- identified and evaluated the family's computer and Internet access;
- taught the young person and family about cyber safety e.g., use of filtering and privacy settings, development of 'house rules' for expected online behaviour, and explanations/discussion of age-appropriate social media;
- provided software and equipment appropriate to meeting the identified goals such as speech recognition software for text entry, word-prediction software or screen-reading software;
- provided training materials such as visual supports, instructions and hands-on training/practice to use the software, equipment or Internet.

The intervention provided opportunities for the participants to gain knowledge and skills in a safe and supported context appropriate to their age and abilities. It also enabled parents to provide support and manage problems in-between home visits. Training was framed to ensure that participants would access the websites identified in their goals in order to engage in social networking with their peers, friends, families and others as necessary. Individual support was provided by the research officer (EG) - a speech pathologist with extensive clinical experience with young people with disabilities and a research background. A research assistant carried out parts of the intervention programme.

At the end of the intervention period, the social networks and the loneliness measures were re-administered.

Results

Since the intervention was individualised for the young people and one-on-one and intensive, a mean number of 11 home visits per young person (SD=3.61) was made over an average of 6.8 months (SD=2.66), with each visit lasting an average 75 minutes (SD=12.34). Since it was home-based, the intervention required travel time and additional work such as ordering specific technology and preparing tailored training materials.

The 18 young people and parents identified a total of 55 problem areas (range 1-5; mean = 3.05). The majority of problem areas identified (37 out of 55, 67%) related to a lack of knowledge and skills around the use of various online social networking (e.g., games, Skype, Facebook, Twitter, videos, email, Livewire). The young people were unaware of strategies for, and lacked opportunities for, socialising. Other problem areas identified (18 out of 55, 33%) related to difficulties with access to the Internet and computer and not being able to independently use the Internet for social networking (e.g., physical access, connection to the Internet, literacy, cyber safety).

Social Networks

Figure 1 shows the mean number of circles of communication partners for Circle 1 to Circle 4 and Circle 6. The participants found it difficult to list the number of unfamiliar partners in Circle 5 such as shop-keepers, waiters and others, but were able to list them in groups. Hence, the mean number could not be calculated. The Circles 1 to Circle 4 partners; there does not appear to be variation between before and after the intervention. The standard deviations for mean number of Circle 3 CCPs (friends and acquaintances) before and after intervention were higher indicating variation among the group. The Wilcoxon Signed Ranks test showed that there was no significant difference between before and after the intervention in the CCPs (Circle 1, $p = .655$; Circle 2, $p = .195$; Circle 3, $p = .900$; Circle 4, $p = .501$).

[41]

Figure 1 - Mean number of circles of communication partners of young people with disabilities.

The online communication partners were individuals that the young people communicated with via Facebook, Email, Skype, Instant messaging, blogs, etc. The communication partners could be from other Circles or just Circle 6. The baseline and post-intervention Circle 6 data from 2 participants were removed as they were considered to be outliers with very high number of CCPs. One participant had 196 "friends" on Facebook at baseline and also communicated on Skype with 10 individuals from other Circles; for another participant Circle 6 baseline data was not recorded through an omission and post-intervention data showed that they had 989 friends on Facebook. Figure 1 shows the mean number of Circle 6 data for the 16 young people before the intervention ($M = 4.31$, $SD = 10.66$) and after the intervention ($M = 26.18$, $SD = 43.08$). The standard deviations are higher indicating high variability within the data.

Figure 2 shows the Circle 6 data for each of the 16 participants in increasing order. Eleven of the 16 did not communicate with anyone online before the intervention and the other five participants had a range from one to 38 communication partners. However, after the intervention, all had online communication partners varying from four to 170. Participant O who previously had zero online communication partners had 78 "friends" on Facebook at the end of the project. The Wilcoxon Signed Ranks test showed that this difference was significant ($p = .000$).

[42]

Figure 2 - Online Communication Partners (Circle 6) before and after intervention.

Loneliness Measure

Figure 3 shows the mean score for the 18 young people on the Loneliness and Social Dissatisfaction Questionnaire before and after the intervention. The mean scores reduced from 34.44 (SD 9.2) to 31.05 (SD 8.7). For five participants with complex communication needs the baseline mean loneliness score was 40.6 (SD 7.4) and after intervention this decreased to a mean score of 32.8 (SD 10.4).

Figure 3 - Mean total raw score on Loneliness and Social Dissatisfaction Questionnaire before and after intervention.

Change in mean ratings for each item on the LSDQC before and after intervention are reported in the Table 2 below. Out of the 16 items that measure loneliness and social dissatisfaction, on 12 items, the mean ratings decreased, indicating that there was a decrease in reported loneliness. On four items, the mean ratings increased, indicating that there was an increase in measure of loneliness. The Paired T-test showed that this difference was not statistically significant ($t(17) 1.531, p = .144$).

Mean Rating of items on Asher Scale	Change in mean rating on Asher scale	Change in Loneliness
I don't have anyone to play with.	-0.67	decrease
It's hard to get other kids to like me.	-0.55	decrease
There's nobody I can go to when I need help.	-0.55	decrease
I don't get along with other children.	-0.44	decrease
I have nobody to talk to.	-0.39	decrease
I am well-liked by the kids in my class.	-0.39	decrease
I don't have any friends.	-0.39	decrease
I feel left out of things.	-0.34	decrease
I have lots of friends.	-0.11	decrease
It's hard for me to make friends.	-0.11	decrease
I can find a friend when I need one.	-0.06	decrease
I'm lonely.	-0.05	decrease
It's easy for me to make new friends at school.	0.11	increase
I'm good at working with other children.	0.11	increase
I feel alone.	0.11	increase
I get along with other kids.	0.33	increase

Table 2 - Change in mean response on loneliness items before and after intervention and reflected changes in loneliness and social dissatisfaction.

A case example illustrates the outcomes of the study. Kate (pseudo name) is a girl aged 16 years 9 months with Spinal Muscular Atrophy (SMA). She is on Level IV on GMFCS, level III on MACS and Level 1 on CFCS. She used a powered wheel chair well and speech and writing for everyday communication. In the initial interview using the COPM she indicated that she wanted to get a connection to the Internet and to be able to socialise online at times that suited her. She did not have access to a computer or Internet independently as she lived away from home due to complex health and family reasons. She was provided with an iPad and Internet connection for 3 months. She was supported to download and use applications such as Safari, Facebook, IMO (instant messaging), and Mail (email) on the iPad to monitor and recharge her Internet account. The training and support required 11 visits with one-to-one support over a period of six months. Kate learned to use Facebook independently and learned to recharge her own Internet.

After the intervention, she reported that she was able to socialise with more people, talked more and was more confident when talking with people on Facebook. She made several new online "friends" who were "friends of her friends" and with whom she felt safe socialising online. She was also able to connect with more people outside of school time and her family whom she had previously been unable to contact by phone. She used Facebook prior to the intervention with the support of others to help her get a connection, but following the intervention was able to use the Internet independently at a time and place that suited her. Her online friends increased from 38 to 159 after the intervention. Kate said:

?because when I've got the iPad I say more things than I do in person because I'm more confident meeting people on Facebook. I made lots of new friends and they're all like friendly and we have good chats.

I'm usually a very shy person but when I'm on Facebook I'm not as shy, I just type. I say more things when I'm on Facebook than I do face to face because I was shy.

They think I'm really cool and nice.

Her score on the Loneliness and Social Dissatisfaction questionnaire showed a slight increase in loneliness from 30 before to 33 following intervention, however, her score is an indication of low loneliness according to the authors (Asher et al. 1984^[38]). On the item, "There's nobody I can go to when I need help," she rated it as "Always true" at baseline and "Hardly ever true" after intervention. For most of the items her ratings were overall positive.

Discussion

The results identified positive benefits of the tailored personal intervention to support personal goal attainment in terms of increasing the number of online social communication partners. These were predominantly with existing offline friends and family, but also included new connections made online. In order to measure these networks using the Circle of Communication Partners, we added a new category – Circle 6 'Online communication partners'.

The increase in Circle 6 online communication partners has to be interpreted with caution as there was high variability within before and after intervention data. For the majority of participants there was a floor effect with no online partners before the intervention. For a few of the participants, after the intervention, the predominant online connection was through Facebook. They communicated with offline or familiar partners from Circle 1 to Circle 4. Two participants had both offline and new online partners through Facebook and Livewire. Few of the participants used only Skype, email or blogging to communicate and this was only with people from Circle 1 to Circle 4. Participants with the lowest numbers of online communication partners after intervention had complex communication needs, poor literacy skills or limited family support. Online communication partners reported by these participants post intervention were predominantly from circle 1 (lifelong communication partners) and circle 4 (paid communication partners).

The post-intervention interview showed that the participants and families were highly satisfied with individualised support and training provided at home (Grace et al. 2012^[32]; Raghavendra et al (in press^[29])). As highlighted by Rhem (2011^[20]) this approach provides parents with a possible strategy to promote the development of social networks for young people with disabilities.

The Loneliness measure showed that overall the group was not "very lonely" at baseline according to the developers of the tool (Asher et al. 1984^[38]). However the subgroup of participants with complex communication needs had a higher baseline mean loneliness score than the overall group. The overall post-intervention score showed decrease in scores in the right direction, however this was not statistically significant. The mean loneliness scores from this study are similar to score reported in an online peer mentoring intervention study by Stewart et al (2011^[28]) who also did not find a significant difference in loneliness measures.

Overall, the increased number of connections in the new Circle of Online Communication Partners did not translate into statistically significant reductions in loneliness measures for this group. This may be explained by the fact that this group mainly connected online with people they already knew offline, and that this interaction was no different to the quality of social connection with these same people offline and so had no overall effect on reducing measures of loneliness. However, out of the total 16 items, 12 reduced in their mean rating. This suggests that the training in online Internet use for social networking purposes may have some impact on some aspects of loneliness in terms of feelings of being connected. It is important to note that the participant group reported generally low levels of loneliness pre-intervention, and majority had minimal physical disabilities and good communication levels. This suggests that it would be good to research the impact on social communication levels and loneliness by targeted recruitment to such an intervention among a group with known higher levels of disability and lower levels of communication and existing friendship networks (such young people may be among those who declined to participate in our study). This research identified that some participants 'collected' a significant number of 'friends' on Facebook. However, this did not appear to translate into any significant difference overall in the level of loneliness reported. Nevertheless, the comment by the one participant suggests that, for some young people, making friends on Facebook could reduce their levels of loneliness and increase their sense of connection.

'Loneliness' may be quite subjective, not always directly related to level of objective social activity (online or otherwise). For example, it is not unknown for very socially active people to describe themselves as lonely, or the reverse. Another issue is the stability of such a perception, whether it fluctuates within brief periods (e.g., over a week). Personality variables (e.g., level of introversion/extroversion, mood or anxiety) and cultural factors (e.g., the value placed on 'popularity') could conceivably influence this. Given the importance of relationships to mental health and quality of life, pursuing an in-depth understanding of loneliness is very worthwhile. More complex factors could be at play in producing these results. Future research could explore the above issues. Research also needs to investigate the impact on social connection and the meaning of 'friends' on Facebook to young people with disabilities who have small friendship networks offline.

Conclusion

The average young person today uses the Internet regularly for social networking. Since young people with disabilities have fewer friends and reduced social networks offline, the Internet holds the potential to be a new way for these young people to extend their social connections. Our research with 18 young people with physical disabilities or acquired brain injury demonstrated that a tailored programme of assistive technology and training in the home significantly increases the number of online communication partners. While this did not in turn reduce measured levels of loneliness overall, it did reduce the level of loneliness associated with 4 individual items on the loneliness scale.

We recommend that future research of this kind be undertaken with a larger number of participants with disabilities, particularly encouraging participation from those with varying initial levels of social connection, and measures of loneliness. We also recommend augmentation with qualitative research to identify the meaning and role of the number and type of online social connections for young people with disabilities, and the contribution these can make to enhancing wellbeing in this group. This will help to identify the extent to which online social networking can be used as a strategy to reduce loneliness and isolation for young people with a physical disability.

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Social networks and loneliness of young people with disabilities

young people

loneliness

disability

social networking

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Links

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