Athletes’, parents’, and siblings’ experiences from the Special Olympics World Games

Shirli Werner

Paul Baerwald School of Social Work and Social Welfare, Hebrew University of Jerusalem, Jerusalem, Israel

Published online: 10 Feb 2015.

To cite this article: Shirli Werner (2015): Athletes’, parents’, and siblings’ experiences from the Special Olympics World Games, Journal of Intellectual and Developmental Disability, DOI: 10.3109/13668250.2015.1010148

To link to this article: http://dx.doi.org/10.3109/13668250.2015.1010148
ORIGINAl ARTICLE

Athletes’, parents’, and siblings’ experiences from the Special Olympics World Games

SHIRLI WERNER
Paul Baerwald School of Social Work and Social Welfare, Hebrew University of Jerusalem, Jerusalem, Israel

Abstract

Background Research supports the importance of sports for people with intellectual disability (ID); however, the unique experience of the Special Olympics (SO) World Games has rarely been examined. The aim of this study was to examine how the SO World Games have affected athletes with ID, their parents and siblings, and the relations between their family members.

Method Twenty-three semistructured interviews were conducted with athletes, parents, and siblings within 9 families upon their return from the World Games held in Athens in 2011. Data were analysed using thematic analysis.

Results Four themes were found. The first theme dealt with the World Games’ role in developing the athletes’ self-identity. The second theme related to the World Games’ positive impact on their family’s quality of life. The third theme related to the World Games’ positive impact on siblings, and the fourth theme related to the importance of participation in the World Games in improving community awareness and inclusion for the 3 groups: athletes, parents, and siblings.

Conclusions The results are discussed and practical implications are highlighted, including the need to increase knowledge and awareness of the SO.

Keywords: qualitative, developmental disability, family quality of life, self-identity, Special Olympics World Games, sports

Introduction

It has been reported that sports contribute to increased enjoyment of life and enhanced quality of life (QoL) for all people (Landers & Arent, 2001) including people with intellectual disability (ID; Bartlo & Klein, 2011). Indeed, research supports the importance of sports for people with ID, including physical (Bartlo & Klein, 2011), psychosocial (Kersh & Siperstein, 2008), and psychological benefits (Harada, Parker, & Siperstein, 2008).

The Special Olympics (SO; http://www.specialolympics.org) is the largest competitive sports organisation in the world for athletes with ID (Gillespie, 2009). SO provides year-round sports training and athletic competition in a variety of Olympic-type sports to individuals with ID. The SO holds ongoing and yearly activities in 185 different countries. Its most important worldwide activity is the World Games, which take place every 2 years.

In the 2011 World Games, nearly 7,000 athletes from 170 countries gathered in Athens, Greece. Despite the importance of the World Games for the athletes and their families, empirical research assessing their impact has been scarce.

Indeed, the majority of research in this area has focused on examining the impact of ongoing specific SO programs such as the Unified Sports Program (Dowling, McConkey, Hassan, & Menke, 2010) or Young Athletes (Favazza & Siperstein, 2006). Previous studies focusing on multinational comparisons, including Costa Rica, Greece, India, South Africa (Dowling, Hassan, & McConkey, 2012), Serbia, Poland, Ukraine, Germany, Hungary (Dowling et al., 2010), United States, Israel, Romania, Azerbaijan, El Salvador, Chile, Venezuela, Panama, Paraguay, Ireland, and Egypt (Favazza & Siperstein, 2006), showed that participation in these programs provides a significant life experience for the athletes,
by improving their physical and psychosocial health (Favazza & Siperstein, 2006; Machek, Stopka, Tillman, Sneed, & Naugle, 2008). For example, athletes participating in SO activities have reported improvements in personal development, social inclusion, equality, and relationships (Dowling et al., 2010), reduced maladaptive behaviours (Favazza & Siperstein, 2006), enhanced QoL (Harada et al., 2008), as well as higher levels of perceived competence, self-efficacy, and self-awareness (Weiss, Diamond, Demark, & Lovald, 2003). Furthermore, the number of competitions in which the individuals participated and the number of medals won was predictive of their general self-worth and social acceptance (Weiss et al., 2003). Studies have highlighted how participation in SO activities has contributed to an increased self-concept (Weiss et al., 2003). Self-concept (also frequently referred to as self-esteem) relates to the perception and evaluation of the self, including the beliefs, feelings, and intentions one holds regarding him- or herself (Sherrill, 1993).

In addition to their effect on athletes, a few studies have examined how participation in SO has affected other family members, especially parents. Benefits included enhanced family relationships and family cohesion (Kersh & Siperstein, 2008), expanded social networks, increased family support (Harada et al., 2008), and greater pride in the child’s accomplishments (Glidden, Bamberger, Draheim, & Kersh, 2011). Furthermore, parents who frequently watched their children compete had more positive parent–child experiences and lower stress than did parents who attended at a lower frequency (Weiss & Diamond, 2005).

One large-scale SO-based study (Kersh & Siperstein, 2008) appraised athletes with ID, their parents, and siblings. This study used a mixed methodology and examined 120 families. It was found that the athletes’ families expressed pride in the athletes’ accomplishments and agreed that SO provided the athletes with a variety of benefits and positively impacted their family life.

Despite the importance of these studies, none of them examined the specific contribution of the World Games. Given that different SO components differentially influence individuals with ID (Weiss et al., 2003), participation in the World Games may be considered a unique experience that includes travelling to a different country, competing at an international level, and being close to media interest (Dowling et al., 2012), all experiences that might affect athletes and their family differently to other ongoing SO activities.

To the best of the author’s knowledge, only one study has focused specifically on the World Games (Dowling et al., 2012), which aimed to define a model for coaching in high-level competitions. Although the researchers examined the personal and social impact of athletes’ achievements, the benefits to siblings, parents, and the entire family system were not examined. Moreover, this study did not focus on examining the family quality of life (FQoL). This is surprising because the studies previously described show that the participation of an athlete with ID may affect the entire family. Thus, the aim of the present study was to examine how the SO World Games impacted the athletes, parents, and siblings, with special attention to their relationship, focusing specifically on how these games affected their FQoL.

FQoL can be defined as the conditions where the family’s needs are met, where family members enjoy their life together as a family, and have a chance to do things that are important to them (Park et al., 2003). It provides a broad and comprehensive framework that addresses the quality of family outcomes and explores those factors that contribute to these outcomes (Werner et al., 2009). FQoL can be described as the aggregated QoL of individual family members, a blend of the QoL that family members bring to the family unit; it is also a discrete group phenomenon (Brown & Brown, 2004). Both of these aspects should be considered in describing the impact of SO on family members and the larger family unit.

The rationale for focusing on parents and siblings derives from two reasons. First, families are recognised as an important social resource for maintaining the functioning and ongoing stability of society (Brown & Brown, 2004). Second, there is a need to fill the gap in knowledge regarding siblings in light of the extensive contradictory body of research showing both negative (Hastings, 2007) and positive (Taunt & Hastings, 2002) effects of having a sibling with a disability.

In sum, this study intends to provide a holistic examination of the impact of participation in the SO World Games both on the individual athlete as well as the entire family unit from the perspective of three groups: athletes, parents, and siblings. This is important because Glidden et al. (2011) demonstrated that different family members may have different perspectives regarding similar experiences. Thus, proxy reporting (i.e., basing reporting solely on the parental perspective) may be problematic and will not expose the entire picture. Accordingly, two main research questions were developed to guide this study:
(1) How did participation in the SO World Games impact individuals with ID, their parents, and their siblings?
(2) How did participation in the SO World Games impact the relationship between all family members and on their FQoL?

Method

Participants

Eighty-four athletes from Israel participated in the 2011 World Games. From information provided by the SO Family Coordinator, 12 families met the criteria of having both parents and siblings attend the World Games. However, for logistic and ethical reasons, it was not possible in this study to contact these specific families directly. Thus, a letter explaining the study aims, along with a consent form, was sent by the SO organisers to parents of all families upon their return from the World Games, asking for the participation of only those families in which siblings and parents attended. After 2 weeks, a second email reminder was sent, after which recruitment efforts ceased. Parents were asked to provide consent for themselves, the athletes, and the siblings. A research assistant contacted consenting parents, and prior to the interview, explained the study to the parents, athletes, and siblings and, at this stage, requested the assent of the athlete and siblings.

Nine families participated in this study. In two families no siblings attended the World Games. Although these families did not meet the research criteria because they had no sibling attending, the author decided to include them and obtain the input of the other family members. In an additional family the sibling who attended the World Games was also an athlete with ID, and given his low communication level, this sibling was not interviewed. Furthermore, in one family the athlete did not participate in the study, as his parents thought that he would have difficulty answering the questions. Because this child was a minor, the author did not attempt to secure assent from him. In sum, the families who participated represented half of the potential eligible families. All families were Hebrew-speaking Israeli families residing in various cities around the country.

A total of 23 interviews were conducted with members of the nine families. Specifically, eight athletes (three males and five females, Mdn age = 21 years, range: 17–25 years), six mothers, three parent pairs (Mdn age = 55 years, range: 27–77 years), and six siblings (four sisters and two brothers, Mdn age = 22.5 years, range: 11–27 years) were interviewed. According to the parents’ reports, three athletes had been diagnosed with learning disabilities, two with Down syndrome, three with autism spectrum disorders (one was not interviewed), and one with an ID accompanied by muscle weakness. The athletes had taken part in SO activities for an average of 7.9 years (SD = 2.6, range: 4–12 years). None took part in unified sports.

Participants were interviewed at their homes by a trained research assistant who was not acquainted with them. All interviews were conducted in Hebrew, audiotaped, and then transcribed. Interview times ranged between 10 and 45 minutes, with longer interviews held with the parents and shorter interviews held with the athletes (since the athletes provided mainly short answers). In order to deal with the short and succinct responses provided by the athletes, all interviews were conducted by an interviewer with experience in the ID field, questions were reworded and, where necessary, parental assistance was provided in clarifying questions and prompts were used by the interviewer as needed. The study’s protocol was approved by the Ethics Committee of the Paul Baerwald School of Social Work and Social Welfare within the Hebrew University of Jerusalem, Israel.

Design

A qualitative interview was conducted with athletes, parents, and siblings using a semistructured interview guide. Separate, but similar, guides were developed for the three groups in order to elicit different perspectives on the issues of interest. Although the author’s preference was to conduct interviews separately with each participant, participants were allowed to choose their preference. Four parents were interviewed alone, four parents were interviewed in the presence of the athlete, and one parent was interviewed in the presence of both the athlete and the sibling; three sibling interviews and six athlete interviews were conducted in the presence of a parent.

The guides were developed for the purpose of answering the two guiding research questions, which were to deepen the understanding of how participation in the World Games affected athletes with ID, their parents, and their siblings, and the relationship between family members and their FQoL. Questions were aimed at eliciting the following key issues: the reasons that parents and athletes wished to participate in the World Games, the participants’ perceptions of the importance of participation in the SO for individuals with ID, determining how participation in the World Games affected the athletes,
parents, and siblings, and how participation in the World Games affected social relationships.

Data analyses

Data were analysed using the principles of thematic analysis (Braun & Clarke, 2006). First, the researcher and a research assistant each familiarised themselves separately with the data. Transcripts were read thoroughly several times, and each noted the initial ideas and thoughts. Second, data that had similar meaning and were related to the same code were denoted on the transcripts. Third, a list of all collated codes was arranged in three files (parents, athletes, and siblings). Different codes were sorted according to themes by categorising the data with similar meaning according to each of the themes. Both researchers went back and forth from the raw transcripts to the generated themes in order to check their fit and the codes were shifted in several instances. Analyses were performed first for each interview and then by examining similarities for each family (i.e., family triads), similarities between type of family member (i.e., across athletes, parents, and siblings) and, finally, by examining similarities for all families (i.e., the entire group). Fourth, themes were re-read and extracts highlighted within the transcripts were re-examined for their fit to the themes. Parallel analyses by the two researchers allowed for crosschecking of various coding strategies and interpretations (Barry, Britten, Barber, Bradley, & Stevenson, 1999). Independent coding and theme selection was followed by discussions about coding within the team to reach a consensus.

All phases of the research and data analyses were conducted in Hebrew. Translation to English took place during the manuscript writing stage. The material was translated by the author and then back-translated by the research assistant using the Brislin (1980) technique. The translation was reviewed to ensure that the meaning of quotes was retained.

Credibility

The reliability of the interpretation of the themes was determined by consensus between the researcher and the research assistant. This is considered an appropriate method for peer debriefing in order to increase the trustworthiness of identified themes in qualitative methodologies (Creswell & Miller, 2000). Further credibility by peer debriefing throughout the entire data analyses and interpretation phases (Creswell & Miller, 2000) was conducted by the author, who met regularly with an academic staff member who is an expert in qualitative research. Both the raw data and themes were discussed with this expert throughout the analysis stage. Furthermore, the credibility of the findings was established via member checking in order to obtain a reflexive elaboration and an enhanced understanding of the research findings. Two SO mothers were asked to review the themes and to state their agreement and any additional thoughts. Mothers were provided with the themes both in Hebrew and, at a later stage with a preliminary draft of the manuscript, in English. Both mothers (independently) agreed to all themes and said that they felt that they had thoroughly described their experiences. Furthermore, a short Hebrew version of the results was sent to all participating families and was also placed on the Israeli SO website in May 2012. Families were openly invited to contact the researcher about any thoughts or questions. No family member contacted the researcher; however, one coach and two researchers from academia contacted her following this posting. Finally, findings were presented at two conferences and in front of the academic staff within the Paul Baerwald School of Social Work and Social Welfare during which the methodology and results were discussed with experienced researchers.

Results

Analyses of the data revealed four major themes: (a) athlete identity formation, (b) the FQoL, (c) the impact on siblings, and (d) the impact on community awareness and inclusion. Each of these themes will be described next, along with quotes to illustrate the theme. The letters A, P, and S designate quotes from athlete, parent, and sibling interviews, respectively. In all cases pseudonyms have been used.

Athlete identity formation

The data revealed that the World Games played a role in helping athletes develop enhanced and positive self-identity, which the author termed an athlete’s self-identity. Several elements contributed to this development: first, recognition of their athletic abilities and pride in their athletic accomplishments motivated athletes to develop an enhanced self-concept. The enhanced self-concept, along with the central importance of sports in their lives, led to the development of enhanced athletic self-identity. These elements are described in this section.

First, the athletes reported that their abilities were recognised and seen by others, especially by teachers and coaches, who frequently initiated the athletes’ participation in the World Games and encouraged
them to continue to improve their achievements. One athlete said: “And then my coach ... she discovered me. She saw my natural talent” (Theresa, A). Showcasing their abilities continued within the World Games and the athletes had an opportunity to strive and reach the top of their athletic abilities. Another example: “People reach the very end of their ability and don’t give up” (Ronit, P). This points to the strong motivation, willpower, and determination of the athletes to continue, succeed, and show their abilities to everyone. Four athletes indicated that their accomplishments were acknowledged regardless if they won or lost: “My friends told me that no matter what, I am always in first place” (Nir, A).

Second, the athletes stressed pride in their personal accomplishments. Medals and ribbons were shown to others as a symbol of pride, since they reflected their achievements and success. This was clear in six of the interviews in which the athletes took time to show the interviewer the medals and ribbons that they had won. Two athletes expanded on this: “I was in the swimming competition. We took the gold in the relay race, I swam backstroke and took the silver, and twice finished in fourth place” (Todd, A). The athletes’ sense of pride in their medals was also noted in a short movie clip made by SO Israel upon their return home, in which they showed off their medals and stated their sense of satisfaction. Furthermore, the medals were used to make their parents proud. One mother recalled that before leaving for the World Games, her son told her, “Mom, do not worry, I will bring you a medal” (Terry, P).

Third, being able to display their abilities contributed to the development of the athletes’ self-concept or self-esteem. Interviews indicated that the World Games enhanced the athletes’ self-esteem because they were able to prove to themselves and to others that they have the ability to endure difficult situations and challenges related to the World Games and are able to achieve success. One athlete said: “To go on. It’s important for me to succeed ... When I was in Athens, I was very good, diligent, responsible ... [the coach] told me to continue. Then she told me that I was perfect, a star” (Kelly, A). One parent captured the essence of this positive experience: “They feel up in the clouds” (Bella, P).

The feelings of enhanced self-esteem were also evident in the athletes’ reports about the respect and positive feedback they received upon their return home. One said: “Friends and teachers ran to me ... excited, and asked me how I am ... and almost wanted autographs” (Michelle, A). Another said: “They told me ’well done, you provided your country with respect” (Theresa, A). This finding will be expanded upon in the section on community inclusion.

Fourth, beyond the recognition of their abilities, pride, and increased self-esteem, it was also found that participation in sports was of central importance to the athletes. Taken together, all of these sources were associated with the athletes perceiving sports as a major and integral part of their self-identity, a theme found strongly for four athletes. For example: “I am an athlete and I like to compete” (Barry, A), and “Suddenly I felt that I am not competing just against people from Israel, I am competing against people that are considered champions in the Special Olympics” (Todd, A). In relation to self-identity, participation in the World Games enabled athletes to accomplish personal goals and achieve greater meaning in their life. One sibling said, “It gives the athlete something to look forward to, something to work hard for, something to be a part of” (Meagan, S). Siblings and parents also regarded the importance of the World Games for identity formation of the athlete, as seen by the diligence and intensity displayed by the athletes. A mother said: “And I told her [athlete], we are finished, you are 23, you have been to the Olympics, enough ... She said, ‘no mom, it’s important to me’ ... We continue because she wanted this” (Sandra, P). Another said:

When she gets up on the platform to swim, she knows that she will be first. Even if she will be last, it makes no difference; she will do everything that she can. It’s as if she is the world champion. (Charley, P)

The positive athlete identity was also important to the siblings and parents: “Compared with the other athletes [with ID], he really sticks out. He looks like an athlete, he acts like an athlete. My friends see him in a different light, he has achievements, he sticks out, and he’s handsome” (Nirit, S).

**Family quality of life**

The theme of the FQoL includes the subthemes of social benefits for parents and siblings, changes in parents’ self-perception, and the personal involvement of parents and siblings in the World Games. These subthemes are described next.

*Social benefits for parents and siblings.* Both parents and siblings described the social benefits that accrued, including social solidarity and the positive experience of meeting other families from around the globe. Parents commented on the opportunity these meetings gave them to learn about services in
other countries, to exchange similar experiences, and to form personal relationships.

Being part of the World Games gave parents and siblings the feeling that they were not on their own, but rather that they felt accepted, and they described feelings of a shared destiny with others who were experiencing similar challenges: “Everything gets erased, differences between nations ... we as parents have the same problems as families in Iran ... Suddenly you see that you are part of many” (Sandra, P). They spoke of the unity within the Israeli delegation, as evidenced by parents cheering all the athletes and not just their own child and going out together after the competitions. Siblings spoke of joint experiences with other siblings whose friends at home could not understand:

The four of us [sisters] are around the same age; the four of us have brothers that are athletes. We went to a pub ... This was a very nice experience because we just spoke about things that I can’t speak about with any of my other friends. No one understands this reality. We spoke of different things that happened to us when we were little. We got beat up quite frequently. These are the types of things that I can speak about with people who know this reality. (Nirit, S)

Changes in parents’ self-perceptions. Parents’ perceptions of themselves were evidently influenced by their early life experiences, which included many challenges as parents of children with ID. In contrast, the World Games were described as a means of providing an outlet of satisfaction to the parents and an opportunity to enjoy their child’s accomplishments.

Seven parents indicated that they invested all of their time and effort on their child with ID. They took pride in themselves as the initiators and facilitators of their child’s achievements. They described changes in their self-perception as parents to a child with an ID, as a result of the child’s participation in the World Games. Their child’s accomplishments in the World Games were perceived as their own success: “This is the peak of our career as parents to a special needs child” (Orna, P). Another said: “In blood, sweat, and tears [hard work] we brought him. He reached ... If he would not have wanted to achieve, he would not have achieved. ... With all of our pushing, and I worked with him, worked, and worked” (Bella, P).

Personal involvement in the World Games. Parents and siblings differed regarding their level of personal involvement during the training period and during the World Games. Seven parents aided the SO effort in different ways, each according to their personal qualifications. None of the siblings reported that they had volunteered in local SO activities. Prior to the World Games, all parents and two siblings reported that they were preoccupied, mainly, with instrumental tasks such as driving the athlete several times a week to their SO training. The training period before the World Games involved supporting the athlete to be physically and emotionally ready for the World Games:

We were logistically involved. Before the journey there were many training sessions and parent meetings. There was a need to prepare him mentally and emotionally, support him, help him, drive him to games and training sessions—all of these preparations both on an emotional and a physical level. (Terry, P)

Four parents perceived SO as an integral part of their family life, with SO activities affecting themselves, the athlete, the sibling, and the community. For example: “We caught the SO fever” (Ronit, P). Within these families the entire family system was found to be highly immersed in the shared SO experience, and much of the daily family schedule and communication was focused on SO activities. For example, “The journey story was discussed at home a lot so that all of our family was involved in thoughts, expectations, and excitement before the trip” (Tommy, P). In addition, to attain the goal of enhancing community awareness, three parents and siblings took an active role by talking about the SO: “We went out and spoke about it all the time and wrote and updated that kind of thing. So the whole community was involved” (Sheryl, P).

Families perceived the World Games as an emotional experience in which the entire family was involved. This was clear in one family in which the sister regarded the excitement the family felt during the World Games to be a joint family experience, which continued upon their return home: “It was much more ... had a much bigger influence ... took us a week after we came back home to come down from the high feelings of excitement” (Boney, S). In a separate interview, the mother regarded the impact of the World Games on additional members of the extended family: “She [the grandmother] told me “thank you, thank you, thank you for including me in this, for letting me be a part of this wonderful experience. It was purely enchanting” (Bella, P). Another sibling mentioned: “I heard about SO so many times, it’s something that is very much spoken about at home, so it was fun taking part in this” (Meagan, S).

Impact on siblings

Enhancement of sibling awareness and knowledge. Taking part in the World Games had a strong
impact on the siblings. Siblings expressed excitement about the unique experience they had, especially viewing the opening ceremony, visiting Olympic sites, viewing the athletes, and feeling part of the SO on a global level. Furthermore, the World Games helped siblings develop more awareness and knowledge about SO and about people with ID. One mother said: “For her [sister] it opened a window to a world that she was not aware that even existed” (Sheryl, P). Siblings spoke of positively changing their own attitudes towards individuals with ID. For example, one sister described spending several hours each day with the SO athletes in a corner for resting that they had arranged for themselves by the pool. When the interviewer asked her “how did this affect you? Did it change something about your way of thinking?” The sibling replied:

   It enabled me to see that even if they are a bit different, they can be very nice and social and be really like your friends. You can speak to them, and listen to them, and play with them. It’s fun. (Cherry, S)

Benefits to the sibling–athlete relationship. Enhancement of the sibling–athlete relationship was reported as one of the main benefits of the World Games. Siblings stated that they came to the World Games in order to provide companionship and support for the athletes: “To give him positive reinforcement and encouragement and be there for him” (Boney, S). Siblings expressed pride regarding the athletes’ accomplishments and were glad that the World Games enabled them to share a joint experience with the athletes:

   I am more involved in what he does. I do not know what he does in school. I know his friends only in terms of “Hi” and “Bye.” This [SO] is something we now have that is familiar to me, we both share this. It was beneficial, it’s nice, and I know more about his life now. (Nirit, S)

Furthermore, the change in attitude described above enabled siblings to perceive the athlete in a more positive light. They were now able to view the athlete’s abilities instead of focusing solely on their difficulties, which led to better acceptance of the athlete. One sibling said, “To some degree, I had more appreciation of my sister’s abilities” (Chandler, S). This enhanced acceptance of the athlete contributed to the stronger bond that developed among the siblings. For example:

   Suddenly she saw the athlete in a different light. She did not see him just in terms of one disability. A very beautiful bond was created. It really improved their relationship, because previously she was very mad at him. Being a sister to a child with difficulties, it’s very difficult, you don’t see the parents’ difficulties … it leads to anger. Now the bond tightened, she really supports him; these are things that did not exist before. (Bella, P)

Parents were hopeful that the strong bond that was created within the World Games would be sustained: “It warms my heart to hear her say that she wants to volunteer in the next Olympic Game” (Sheryl, P). A second mother explained: “I think that for his sister it was a revolutionary change because she returned so emotionally excited and she really wants to be involved with him in the present and in the future” (Ronit, P).

Community awareness, inclusion, and acceptance

As opposed to the general community, within the World Games the participants felt that the athletes experienced solidarity and a sense of belonging and that it enhanced their feelings of inclusion and acceptance as being equal to others. For example, “because others accept athletes in the SO like they are” (Terry, P). During the World Games, the athletes were described as being at the centre of focus, which enhanced their self-esteem and pride:

   It was just for them, they ruled the city. It’s incredible, it changes their lives, without a doubt. The city is full with 7,000 athletes, and they all feel that they are the best. They walk around with their medals, and feel proud, with their chest out. (Meagan, S)

These feelings of inclusion were reflected in the cheering and hand clapping that the athletes received. One parent said: “Usually no one claps for them, usually they are at the margins of society. Who even pays attention to them? What can they provide to society? And there, in that moment, they are equal to everyone” (Sandra, P). Other parents perceived inclusion merely as an opportunity that the child can partake in “normative” activities. The World Games provided those individuals who would not have had such opportunities elsewhere with an equal opportunity to participate in sporting events: “This is the closest thing to something normal that every normal [sic] person can do … it’s a real event” (Ohad, P).

Parents reported feeling more included in their home community including friends, neighbours, families, and schools. In contrast to their previous negative community experiences, parents strongly emphasised the positive treatment given by their
communities to the athletes upon their return. Four parents spoke of the certificates, medals, or cups given to the athletes by friends or cities in which they reside: “They [the village where the family lives] sent her an award that said ‘you’re our hero’” (Sandra, P). Others commented on the articles written about them in the local newspapers: “They go and represent the country and bring back medals, so that’s good, it looks good on TV” (Orna, P).

Nevertheless, positive feelings of enhanced community awareness were also accompanied by frustration. Participants reported that the lack of community awareness and knowledge of the SO currently continues, with people’s image of the SO as being open only to people with ID when, in reality, in Israel people with other developmental disability can also participate. One sister said:

The newspaper prefers to take pictures of individuals with Down syndrome, and not people that look like my brother; that is, an ordinary kid in every aspect … He opens his mouth and you can hear that something is a little different, but, in the end, he looks completely normal. This marketing is not good. (Nirit, S)

The participants asserted that this lack of awareness resulted in low participation in SO activities. Three parents were not familiar with SO activities prior to their participation in the World Games. They suggested the need to encourage more families to participate in these activities and to raise community awareness about the SO. One athlete expanded:

They just hear the name [SO], and are turned off by it. They need to know more about what is SO because it’s a special thing that not everyone can take part in, and more people need to focus on this, people that have strength and power, and that will get into it and also donate. (Todd, A)

**Discussion**

The aim of the present study was to examine how participation in the SO World Games impacted the athletes, their parents, and siblings, with special attention given to the relationship between athletes, their parents, and siblings and their QoL. Overall, the results indicated the positive impact of SO on athletes, their parents, and siblings; this is consistent with previous research (Glidden et al., 2011; Kersh & Siperstein, 2008; Weiss & Dykens, 2008). The findings add additional and unique information regarding four aspects: athlete identity formation, the FQoL, the impact on siblings, and community awareness, inclusion, and acceptance.

**Athlete identity formation**

The finding that athletes felt that their abilities were recognised by others and took pride in their accomplishments is in line with previous research showing that feelings of competence in social and activity domains are important for individuals with ID in developing a more positive self-concept (Zetlin & Turner, 1988). The notion that a sense of achievement improves the self-concept has been explained in previous SO studies, which have suggested that participating in competitions increases an athlete’s sense of self-worth because it represents personal effort and successfully meets the challenges of a task. Success brings about feelings of confidence, which consequently brings about a sense of self-worth and accomplishment (Weiss et al., 2003).

The finding that sports were perceived as a major and integral part of the athletes’ self-identity is in line with previous studies showing that sports provide an opportunity for identity-related experiences and for self-defining exploration (Iman & Boostani, 2012). Specifically, participation in SO activities has been found to have a positive impact on the development of an athlete’s self-concept (Weiss et al., 2003). The contribution to an athlete’s identity is important because studies of youth with physical disability have shown that developing a sense of identity may be complicated due to societal constraints that limit this group’s opportunities to engage in and explore identity-forming activities (Groff & Kleiber, 2001).

In the sports science field an athletic identity has been defined as the degree to which an individual identifies with the role of an athlete and looks to others for acknowledgement of that role (Martin, Adams-Mushett, & Smith, 1995). Individuals with strong athletic identities establish salient self-identities by their development of skills, confidence, and social interactions during sport. Furthermore, successful performance enhances this self-concept (Shapiro & Martin, 2010).

The current findings that the SO World Games provide an opportunity for identity formation may be related to the intensity of the participation during the time of the World Games in comparison with daily life. Identity formation was possible because the athletes found that the SO fits their interests and talents. Furthermore, sports constituted a big part of the athletes’ daily life, and it was clear that this activity was highly important for those
athletes who strived to reach goals and get the best out of themselves.

The theory of athletic identity has shown that it may include both public and private identities. Public identity relates to the way a person describes himself or herself, given the external rewards associated with being an athlete, such as attention and public approval. Private identity relates to thinking and feeling like an athlete and viewing sport as an outlet for self-expression (Shapiro & Martin, 2010). Both of these aspects emerged in the current study. Public identity can be shown by the importance that athletes place on showing their abilities to others and showing their winnings through medals and ribbons. Private identity was shown in accomplishing personal goals and in achieving an inner feeling of being an athlete.

Family quality of life

The results indicate that beyond individual QoL, participation in the World Games contributed to enhanced FQoL. In line with FQoL theory (Park et al., 2003), the findings showed that the World Games positively influenced meeting the family’s needs, enjoying their life together, and having an opportunity to do things that are important to them. First, meeting a family’s needs was shown by the opportunities for social meetings with other families, exchanging similar experiences, and feeling accepted. Enjoyment of life together as a family was shown by the parents’ satisfaction in viewing the athletes compete. Furthermore, doing things that are considered important to the family as a unit was shown by the parents’ reporting of the World Games as being integral to the entire family and the deep involvement of family members in experiencing the World Games.

Furthermore, FQoL theory posits that the QoL of one family member might greatly affect the QoL of other members (Wang & Brown, 2009). The findings of this study indeed indicate that the impact of the athletes’ participation and achievement in the World Games went beyond the individual, and this was also reflected in the wellbeing of the parents and siblings. For example, the achievements of the athletes were also perceived as achievements of the parents, resulting in increased parental self-esteem. Both parents and siblings were proud of the athletes and happy to see their joy and acceptance as individuals.

FQoL theory also posits that the family is a unit in which its members live their lives collectively, as realised in the family interactions in day-to-day life (Wang & Brown, 2009). In line with this, the results of the present study suggest that the World Games played a strong role and had meaning in family life. This is shown by the deep involvement, both instrumentally and emotionally, of family members in the World Games.

Impact of the World Games on siblings

The results of this study add to the current literature showing that siblings play an important role in the lives of individuals with ID, given their long-lasting close relationships (Heller & Arnold, 2010). In this study, siblings reported the benefits of participating in the World Games, their shared experience, and the effect of the SO World Games on the relationships between family members, by providing them with a new, more positive picture.

Community awareness, inclusion, and acceptance

Enhanced community inclusion is an important finding in this study, pointing to improved acceptance of individuals and family members within their communities. Previous FQoL studies have found that families of individuals with ID frequently report having limited opportunities to receive support from other people (Werner et al., 2009). Furthermore, although families find importance in community interactions, they report lower initiatives to achieve this FQoL domain (Bertelli, Bianco, Rossi, Scuticchio, & Brown, 2011). These findings may result from stigmatic attitudes held by individuals in society, which result in exclusion and distance from persons with ID and their families. Furthermore, family members may also distance themselves from others because of the fear of being prone to stigma and negative behaviours (Werner & Shulman, 2013). Thus, the results shed more positive light, showing that participation in the World Games positively contributed to individuals and families feeling more accepted in society. This may be related to SO’s ability to improve the attitudes of others within the community, a notion that should be more deeply scrutinised in additional studies.

The results, in line with previous SO studies, highlight the importance of SO in promoting awareness about people with ID and changing the public’s attitudes (Dowling et al., 2010). Nevertheless, the results also clearly show that negative stereotypes, lack of community awareness, and lack of inclusion are still widespread in Israel. Apparently, the way in which SO activities in Israel are currently structured leads to the lack of true social inclusion, since most of the activities are segregated and there is a lack of unified activities. Although families benefit from
and enjoy these activities and feel that they provide an opportunity for normative activities, these separate activities do not fully support Article 30 of the Convention on the Rights of Persons with Disabilities (UN General Assembly, 2007), which urges participation in mainstream sports activities. Thus, it is suggested that the development of unified sports activities, which are presently lacking in Israel, be more aggressively promoted, since personal exposure to individuals with disability has been found to be useful in efforts to change stigma. Moreover, the media should be used more frequently as a vehicle to reinforce to the public the abilities and strengths of individuals with ID.

Conclusions and implications

Several limitations need to be taken into account in this study. First, although a qualitative study does not seek random selection, the families who travelled to the World Games, and especially those who took part in this study, may represent a highly selective and enthusiastic group. In addition, the sample size was relatively small, although it represented half of the families that met the inclusion criteria. Second, the interviews with athletes were relatively short but similar to the typical length in other qualitative studies with persons with ID (Finlay & Lyons, 2001). Although lengthier interviews may have enabled the author to collect richer actual experience, the information collected, nevertheless, is important to this field of research. Third, it is possible that parents and siblings may have provided an overly positive response; thus, the author interviewed athletes and did not rely solely on parental reports. In addition, some of the athlete and sibling interviews took place in the presence of their parents. This could potentially influence their responses if the parents were to make overt or derogatory comments. Nevertheless, in all interviews the parents merely helped their children in understanding the interview questions and made no critical comments that were noted by the researchers. Fourth, member checking was performed with only two mothers, which was considered sufficient because credibility was examined in several ways. Fifth, this study was conducted at one point in time and focused on the specific peak experience of the World Games. Thus, it was not possible to examine whether the themes highlighted, such as the enhanced relationships between family members, were sustained over time. Furthermore, it was not possible to compare these experiences and the experiences from ongoing general yearly training.

Despite its limitations, in terms of conceptual implications, this study adds to this area of research by examining the perspectives of different individuals within the same family who were given an opportunity to reflect on their own experience. Furthermore, the study is the first to examine relations among athletes, siblings, and parents as a result of participation within the peak event of the World Games.

In terms of practical implications, given its positive influence, a high priority should be given to increasing knowledge and awareness about the SO within the greater community and within families that have a member with an ID. In addition, it is clear that it is important to introduce more unified sports activities in order to bring about true social inclusion in Israel to a greater degree. Within countries in which unified sports already exist, there is a need for ongoing evaluations to ensure that programs indeed achieve true community inclusion. This includes, for example, evaluating whether each member of the team has an equal chance to play a valued role within the team and to ensure that athletes with ID are provided with a chance to socialise with peers and to form friendships. Note that different individuals with ID have different interests, not necessarily sports. It is therefore important to explore, jointly with each individual, what types of activities are personally important to them, and to allow the individual to make an autonomous choice while providing appropriate opportunities to engage in those activities.

Future research should examine the prospect of additional stakeholder groups, including volunteers, coaches, sports organisations, sports funding bodies, and the general public, regarding the importance of SO activities and toward the possibility of increasing the inclusion of individuals with ID in sporting activities. In addition, a future study should return to the participating families to determine whether the changes reported have been sustained. Finally, future studies should contrast between actively involved and less actively involved families within regular ongoing SO training sessions and focus on the influence of sports participation on the quality of family relationships.

Acknowledgements

I would like to thank all individuals who participated in this study and SO Israel for their cooperation and help in conducting this study.

References


