# Collaboration in early childhood intervention services in Gauteng: Caregiver perspectives

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#### **Abstract**

A central tenant of early childhood intervention (ECI) is collaboration between professionals and the caregivers of children receiving these services. There are limited studies on caregiver perceptions of collaboration in ECI teams particularly in resource-limited countries. Sixty-four caregivers participated in this study by completing a questionnaire on their perceptions of collaboration in ECI services in South Africa. The questionnaire survey was administered in a group setting by a trained research assistant who was proficient in the Setswana language. The results revealed that caregivers have a good understanding of collaboration in ECI services. However collaboration, in relation to family-centered practices appeared to be undervalued by caregivers. These results are discussed and the limitations of the study as well as future recommendations are outlined.

*Keywords*: Caregiver perceptions; children with disability; collaborative teaming; family-centered intervention; resource-limited; survey; translation

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Collaboration is central to the success of Early Childhood Intervention (ECI) teams, particularly when addressing the diverse needs of children with disabilities or those at risk for developmental delay and their families (Dinnebeil, Hale, & Rule, 1996; Edelman, 2004; Moeller, Carr, Seaver, Stredler-Brown, & Holzinger, 2013). Collaboration enables families and professionals to work together or interact with each other towards a common goal (Bedwell et al., 2012) involving processes of sharing, partnership, interdependency, and simultaneous empowerment (D'Amour, Ferrada-Videla, San Martin Rodriguez, & Beaulieu, 2005). In this study, collaboration refers to the interpersonal relationships and factors influencing these relationships between team members such as professionals and family members/caregivers in an ECI team (Harbin, McWilliam, & Gallagher, 2000; Klein & Gilkerson, 2000) who are engaging to achieve a mutual goal (Bedwell et al., 2012).

Collaboration between professionals (such as nurses, physiotherapists, occupational therapists, social workers, doctors, speech-language therapists) (Eldar, 2005; Xyrichis & Ream, 2008) and the family member is essential (Briggs, 1997; Shonkoff & Meisels, 2000). The family member, often a parent, or the primary caregiver, is regarded as a pivotal member and decision-maker in the team (Klein & Gilkerson, 2000; WHO, 2009; Rowe & Moodley, 2013). In South Africa, the "primary caregiver" of children requiring ECI services is broad and may include a sibling or a member of the extended family such as a grandparent, a relative, or an unrelated person including a neighbour (Schlebusch, Samuels, & Dada, 2016).

Collaboration in ECI services benefits professionals and families they serve, including a reduced turnover of staff, better quality and more comprehensive services, less duplication of services, and more efficient administrative procedures (Eva, 2002; Patel, Pratt, & Patel, 2008; Moore, 2008; Xyrichis & Ream, 2008). Family-professional collaboration has the potential to influence outcomes for all family members, not only the child with a disability (Keen, 2007). Families are able to save time because services are not fragmented (Edelman,

2004). Moreover, the collaborative partnership with professionals increases a sense of self efficacy in families (Trivette, Dunst, Boyd, & Hamby, 1995). Families and professionals are also less stressed and more satisfied (Edelman, 2004), leading to greater success in family-professional partnerships (Doyle, 2008; O'Neil, Ideishi, Nixon-Cave, & Kohrt, 2008).

## Caregiver role in collaboration

Caregiver voices in ECI literature are recognized as fundamental and through their inclusion in collaborative teams, caregivers become instrumental in articulating what and how services should be delivered for their child and family. This mandates caregivers as key decision-makers and equal partners in the collaboration process (Bailey, Raspa, & Fox, 2012; Moeller et al., 2013).

# **ECI in South Africa**

It is estimated that 2.1 million children (11.2% of the total child population) in South Africa have a disability, of whom 28% are between 0-4 years, and 10% are between 5-9 years (UNICEF, 2012). An overwhelming 11.9 million children (64% of all children) and their families are living in poverty (UNICEF, 2012). This is further compounded by the HIV/AIDS epidemic, which accounts for 30%-40% of deaths in children younger than 5 years (Eley, 2010). When children and families exist within these contexts, (Saloojee, Phohole, Saloojee, & Ijsselmuiden, 2006), disability together with the accumulation of environmental risks has the potential for increasingly adverse effects on children's development (Grantham-McGregor et al., 2007). This in turn leads to increasing numbers of children requiring ECI services (Jacobs, Shung-King, & Smith, 2005).

Whilst the need for ECI services is apparent, ECI is a relatively new approach to service delivery for young children with disabilities and their families in South Africa (Samuels, Slemming, & Balton, 2012). Internationally ECI services are defined as multiprofessional services directed at young children (between the ages of zero to six years) with a

Running head: COLLABORATION WITH CAREGIVERS IN ECI SERVICES IN GAUTENG, SOUTH AFRICA disability or who are at a risk for developing disabilities, and their families. These services are implemented to reduce developmental delays, prevent functional deterioration, and promote children's health and family functioning (Bruder, 2010; Diken et al., 2012; Pinto et al., 2012; Shonkoff & Meisels, 2000). In South Africa, however, ECI services are mainly provided to children with disabilities between 0-6 years of age, often excluding those "at risk" since these children are not effectively monitored in healthcare services (Samuels et al., 2012). Children and their families access ECI services via public healthcare settings, which is the focus of the current study. This may be attributed to approximately 68% of the population depending on this sector (Rowe & Moodley, 2013), including children from birth to six years

In South Africa, ECI services for young children with disabilities and their families are mostly provided on a monthly basis by a variety of professionals. These services typically follow a multidisciplinary (Uys & Samuels, 2010) or interdisciplinary model (Samuels et al., 2012) similar to general medical services provided in healthcare settings. Whilst ECI services are available, caregiver's ability to access these services is often limited, which can be partly attributed to the remnants of South Africa's apartheid legacy as well as the fragmentation of services in healthcare settings (Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2009). The apartheid legacy has systematically disadvantaged, oppressed, disempowered, and stripped black people of their autonomy in intervention and rehabilitation services (Coovadia et al., 2009; Rowe & Moodley, 2013).

being eligible for free healthcare (National Health Act, 2003).

Caregiver autonomy and their role in decision-making in healthcare services has more recently been advocated in the country through the advent of South Africa's Consumer Protection Act effected in 2008 (Rowe & Moodley, 2013). Caregivers or families often still struggle to perceive themselves as equal partners and decision-makers within rehabilitation services. The relationship between professionals and caregivers is further complicated in that

Running head: COLLABORATION WITH CAREGIVERS IN ECI SERVICES IN GAUTENG, SOUTH AFRICA the vast majority of professionals in South Africa still emanate from white, middle-class, English-speaking backgrounds, and thus intervention may not always be given in the child and family's home language (Pillay & Kathard, 2015). Caregivers in this context also often encounter difficulties attending ECI services due to financial constraints, as well as time and support demands (Saloojee et al., 2006).

# Variables influencing collaboration in ECI services

Dinnebeil, Hale, and Rule (1999) argue that if establishing a collaborative relationship with families is important, then identifying the factors that influence collaboration between the professional and families would be valuable. The literature indicates that both interpersonal skills and organizational variables are associated within family-centered care (Dinnebeil et al., 1996, 1999; Yang, Hossain, & Sitharthan, 2013). These variables include involving caregivers as key decision-makers in ECI teams (Dinnebeil et al., 1996), ensuring services are based on the needs of the child and family (Turnbull, Turbiville, & Turnbull, 2006), and the linguistic (Bornman, Sevcik, Romski, & Pae, 2010; Penn, 2007), and cultural (Barrera & Kramer, 1997) congruency between professionals and caregivers.

In South Africa, many professionals lack experience in working cross-linguistically and also struggle to interact with families from different cultures. Successful team collaboration is further impeded by families' experiences of poverty (Govender, Reardon, Quinlan, & George, 2014; Saloojee et al., 2006), which may inhibit the degree to which families freely express their cultural beliefs and behaviours (Barrera & Kramer, 1997). Professionals may not have been trained to work with caregivers from different linguistic and cultural backgrounds, including those living in poverty (Corr, Santos, & Fowler, 2015). Organizational variables influencing collaboration include training and experience in working with families and children (Briggs, 1997), support from the organization (Batorowicz &

Shepherd, 2008) including time, financial and human resources (Coovadia et al., 2009; Briggs, 1997) are also essential for successful collaboration in ECI teams.

Additional factors influencing caregiver-professional relationships include the efficiency of communication between team members (Buljac-Samardzic, Van Wijngaarden, Van Wijk, & Van Exel, 2011; Blu-Banning, Summers, Frankland, Nelson, & Beegle, 2004), whether team members respect each other (Espe-Sherwindt, 2008), and are committed to the team (Yang et al., 2013), and how goals are set between team members (Yeboah- Antwi et al., 2013). For example, in a study focusing on collaboration between six adolescent mothers and their professionals in an early intervention team (Lea, 2006) found that caregivers were dissatisfied with ECI services because there was lack of trust, respect, and equal decisionmaking powers between team members. In contrast to these findings, Crais, Roy, and Freeman (2006) in a study with 134 early interventionists (across a variety of disciplines) and 58 family members from centers that involved evaluations, intervention, and home-based programs, found that caregivers were satisfied with the collaboration in the team, especially with the communication and exchange of information between team members. Thus, there still remains a gap in our understanding on how families and professionals collaborate (Clarke, 2010; Zwarenstein, Goldman, & Reeves, 2009), with limited information on how families and professionals collaborate within ECI services (Yang et al., 2013).

Taking into account the contextual factors that may affect caregivers' participation and satisfaction with collaboration, unemployment and poverty, combined with South Africa's ECI service delivery context, lack of resources, linguistic and cultural diversity, as well as the country's historical legacy, it is not yet known how caregivers of children in ECI services in South Africa perceive family-professional collaboration in ECI services. Therefore the aims of this paper were:

- To describe caregivers' perceptions of collaboration in ECI services in the Gauteng province of South Africa.
- To explore relationships between caregivers' perceptions of collaboration and participation in and satisfaction with services.

## Method

#### Research design

A descriptive survey design was utilized to describe caregivers' perceptions of collaboration in ECI teams. A caregiver survey questionnaire was administered in a group by a trained research assistant who was proficient in the Setswana language. The research assistant read each question in the questionnaire, while the caregivers recorded their responses independently on their own copies of the questionnaire. This approach was chosen because it eliminates bias against caregivers who may have had difficulty with written questionnaires (McMillan & Schumacher, 2006).

# **Participants**

Caregivers attending early childhood services with their children at public hospitals and clinics in the city of Pretoria, in the Gauteng province of South Africa were selected. Public hospitals and clinics were selected as research sites, because the majority of people in South Africa access general health services, including ECI services, in these settings for their children with disabilities (0-6 years) (Statistics South Africa, 2015). Gauteng Province (in which Pretoria is based) has the largest number of children with disabilities (24.7%) in comparison to the other provinces in South Africa (Statistics South Africa, 2015). Purposeful sampling was used to recruit participants at these sites as they had to meet the following selection criteria: a) caregiver has a child between 0-6 years attending ECI services at public hospitals and clinics, b) caregiver should have attended ECI services for a minimum of six months, and c) caregivers' home language is Setswana or the caregiver is competent (read

Running head: COLLABORATION WITH CAREGIVERS IN ECI SERVICES IN GAUTENG, SOUTH AFRICA and understand) in Setswana as it is a predominant African language spoken in Pretoria, South Africa (Statistics South Africa, 2012).

Of the 15 institutions (eight hospitals and seven clinics), four hospitals and three clinics provided permission to participate in the study. Coordinators from each institution provided the researcher with a list of potential caregivers attending the ECI service on a particular date. A total of 75 caregivers were identified of which 11 did not arrive on their appointment date. Hence, 64 caregivers who met the selection criteria were identified at the site. All 64 caregivers consented to participate in the study.

Table 1 presents descriptive information for both the caregivers and children receiving ECI services. The majority of caregivers accessed ECI services in a hospital healthcare setting (73%). Furthermore, the majority of caregivers were mothers (92.2%), with a Black ethnic background (98.4%), had completed Grade 12 (59.4%), and were between 20-30 years of age (46.9%). Whilst the home language of 28.1% (18) of the caregivers was Setswana, the remaining 71.9% (46), whose home language was not Setswana, could read and understand Setswana. Approximately 64.1% of the caregivers were single and unemployed. Most common diagnoses or medical conditions of the children attending ECI services were delayed development and Cerebral Palsy.

**Table1.** Descriptive information of caregivers and child receiving ECI

Description	Category	N	%
Setting in which caregivers accessed	Clinic	17	26.6
ECI services	Hospital	47	73.4
Caregiver relationship to the child	Mother	59	92.2
	Father	1	1.6
	Grandmother	3	4.7
	Guardian/Primary caregiver	1	1.6

Description	Category	N	%
Number of children in the household	One child	19	29.7
	Two children	21	32.8
	Three children	10	15.6
	Four children	8	12.5
	Five or more children	6	9.4
Ethnic background	Black	63	98.4
	Coloured	1	1.6
Age of caregiver	15-19	2	3.1
	20-30	30	46.9
	31-40	18	28.1
	41-50	13	20.3
	51-60	1	1.6
Home language	English	1	1,6
	Afrikaans	0	0
	Setswana	18	28.1
	Sesotho	8	12.5
	Sepedi	21	32.8
	Other: isiZulu (4), isiXhosa (1),	16	25
	Xitsonga (7), Tshivenda (1), and		
	IsiNdebele (3)		
Caregiver competency in reading and	English	44	68.8
understanding languages other than	Afrikaans	6	9.4
their home language	Setswana	46	71.9
	Sesotho	18	28.1
	Sepedi	12	18.8
	Other: isiZulu (13), IsiXhosa (2),	20	31.2
	Xitsonga (1), Tshivenda (1), Siswati		
	(1), and IsiNdebele (2)		
Marital status	Married	19	29.7

# Running head: COLLABORATION WITH CAREGIVERS IN ECI SERVICES IN GAUTENG, SOUTH AFRICA

Description	Category	N	%
	Never married	41	64.1
	Separated	2	3.1
	Divorced	1	1.6
	Widowed	1	1.6
Highest level of education	Grade 10 or lower	22	34.4
	Grade 12	38	59.4
	Diploma	2	3.1
	Postgraduate certificate	2	3.1
Employment status	Full time	9	14.1
	Part time/casual worker	14	21.9
	Unemployed	41	64.1
Age of child receiving ECI services	Less than one year	8	12.5
	One year	11	17.2
	Two years	11	17.2
	Three years	12	18.8
	Four years	3	4.9
	Five years	5	7.8
	Six years	14	21.9
Gender of child	Male	39	60.9
	Female	25	39.1
Disability/Medical condition of child	Delayed development	33	52.4
	Cerebral palsy	13	20.6
	Prematurity	5	7.9
	Down syndrome	3	4.8
	Autism	2	3.2
	Other	7	11.1

# **Survey instrument**

The collaborative practice in ECI parent questionnaire (Yang, 2010) comprising six domains and 92 items was adapted and translated for the South African context. Malmgreen's (2005) five-step procedure for validating a tool from another English-speaking country was used. A comprehensive process of face and content validation involving six panel reviews which included caregivers, professionals, and local ECI academic experts were used for this process. With respect to face validity, changes were made to the terminology used in the parent questionnaire to ensure greater familiarity to caregivers in South Africa. Fourteen items (including the domain on "suggestions for collaboration" with 13 items) were deleted due to the recommendations of the panels as well as to shorten the questionnaire, resulting in five domains and 78 items.

Content validity was determined through establishing the Content Validity Index (CVI) of the parent questionnaire in order to revise, delete or substitute items in the questionnaire (Lynn, 1986; Polit & Beck, 2006). A minimum of three experts, as suggested by Lynn (1986), was used, and all items were required to meet the CVI criteria of 1.0; that is, 100% (Lynn, 1986). From the 78 items, two items were deleted as they did not meet the CVI criteria of 1.0, resulting in 76 items being in the final questionnaire. Thereafter the revised caregiver instrument was translated into Setswana. The translation process by Peña (2007) was utilised and involved obtaining linguistic, as well as functional, metric, and cultural equivalence. The adaptation and translation process of the collaborative practice in ECI parent questionnaire (Yang, 2010) resulted in the instrument used in this study which is referred to as Collaboration in Early Childhood Intervention Caregiver Revised [CECI-C(R)]. The CECI-C(R) was pre-tested in a pilot study with five caregivers. Results of the pilot study included recommendations to the participant selection criteria (e.g. the ability to read and

Running head: COLLABORATION WITH CAREGIVERS IN ECI SERVICES IN GAUTENG, SOUTH AFRICA understand Setswana was included as a criterion) and the item related to obtaining information on the child's disability was rephrased to enhance clarity.

The CECI-C(R) comprises five domains which assessed caregivers' perception of the i) understanding of, ii) advantages of, iii) difficulties with, iv) factors influencing, and v) outcomes of collaboration. The CECI-C(R) consisted of 76 items of which 72 were closed-ended statements and four open-ended questions. The response format for the CECI-C(R) included a five-point Likert scale except for two items in the "Understanding of Collaboration "Domain which uses a four-point Likert scale. The five-point Likert scale ranged from 'strongly disagree to strongly agree', 'extremely unimportant to extremely important', 'extremely dissatisfied to extremely satisfied' and 'extremely effective to not at all effective'. The ratings for the four-point Likert scale was 'high, medium, low, none'. All domains included an open-ended question, except for the "Understanding of collaboration" and "Effectiveness of collaboration." Where included, the open-ended question was used to obtain additional information on the particular domain. Table 2 presents the domains and sample items for each domain in the CECI-C(R).

**Table 2.** Examples of items in CECI-C(R)

Domain	Sample items
<b>Understanding of Collaboration</b>	Do you think
	Parents should be included in the team providing services to young children.
	Working together effectively requires open communication (e.g. all
	information is shared).
	Participation in collaboration:
	How involved are you in the team providing a service for your child?
	How willing are you to work in a team?
Advantages of collaboration	Do you think working together in a team CAN

Domain	Sample items
	Help parents to access the services (e.g. Speech-Language Therapy,
	Occupational Therapy) needed.
	Improve the quality of life of children and families.
Difficulties with collaboration	Professionals lack of understanding of family needs.
	Professionals lack of awareness of the family's culture.
Factors influencing relationships in a team	How important is it for working effectively in a team?
	Organizational factors:
	Time for working together in a team
	Sharing of information
	Interpersonal factors:
	Mutual respect amongst team members
	Showing concern for family needs
Outcomes of collaboration	How satisfied are you with
	Professionals working together in the team.
	The opportunities to interact with other families.

# Procedure

Approval from the Ethics Committee of the relevant University in South Africa was obtained, as well as appropriate permissions from the provincial Department of Health and consent from the hospitals and clinics accessed in this study. Informed consent was obtained from the caregivers. Data collection occurred at the hospital/clinic where caregivers attended ECI services as this was considered to be a convenient location for participating caregivers. The caregivers were divided into groups, ranging between two to eight per group depending on the number of caregivers attending the clinic on the particular day. The group session was then held in a quiet area, in a room that was allocated to the researcher. The digital tape recorder was started once data collection commenced. Each caregiver was provided with a survey pack and a pen. A research assistant competent in Setswana then administered the

CECI-C(R) to the caregiver group following a procedural script developed for the study. A total of 31 group sessions were conducted.

The research assistant sat in front of the caregiver group and read out the introduction. Thereafter, the assistant read out each question and allowed caregivers approximately  $\pm 5$ -10 seconds to complete the question independently. She repeated the question when requested to do so. Once the group session was completed, all questionnaires were collected. The caregivers were then thanked for their participation and were each provided with a token of appreciation which included a travel stipend and a sweet pack for the child. Caregivers were also given the opportunity to ask the researcher and research assistant questions.

# Reliability

A procedural checklist was developed to measure procedural integrity for the group sessions. Schlosser (2005) recommends that between 20% and 40% of sessions should be scored for procedural integrity. Two independent raters, with Setswana as their home language, listened to 30% of the audio recordings and completed the procedural checklist in order to determine the procedural integrity for data collection with caregivers. From the group data collected, 99% reliability on procedures was achieved. The internal consistency reliability of the CECI-C(R) was assessed by calculating Cronbach's alpha. It is recommended that the coefficient alpha should be greater than or equal to .70 - .80 (Field, 2013). A score of .89 was achieved, indicating high reliability (Maxwell & Satake, 2006) which implies that the CECI-C(R) has the potential to provide reliable data on collaboration if used in the South African context. The Cronbach's alpha for each domain is presented in Table 3.

**Table 3.** Domains and descriptive statistics of CECI-C(R)

<b>Domains of CECI-C(R)</b>	Mean	SD	Number	α	Interpretation
			of items		
Domain 1: Understanding of collaboration	4.33	0.40	9	.65	Acceptable
Domain 2: Advantages of collaboration	4.66	0.35	10	.84	Good
Domain 3: Difficulties with collaboration	2.47	0.74	9	.81	Good
Domain 4: Factors influencing collaboration					
-Organisational factors	4.44	0.52	9	.79	Good
-Interpersonal factors	4.56	0.42	19	.91	Excellent
Domain 5: Outcomes of collaboration					
-Satisfaction with collaboration	4.31	0.70	5	.84	Good
-Effects of collaboration	4.55	0.46	7	.82	Good
-Effectiveness of collaboration <sup>a</sup>	4.56	0.57	2		

<sup>&</sup>lt;sup>a</sup> This sub-domain is based on single items (Yang, 2010); therefore an alpha is not presented.

## **Results**

The results are discussed in relation to the domains of collaboration: understanding of collaboration, advantages of collaboration, difficulties with collaboration, factors influencing collaboration, and outcomes (satisfaction, effects, and effectiveness) of collaboration. The overall means and standard deviations for each domain are presented in Table 3.

# **Understanding of collaboration**

Nine questions were asked to determine caregivers' understanding of collaboration. Two items received the highest mean scores, namely, "professional's opinions about working together in a team are important for successful interaction with parents" (M = 4.70, SD = 0.46) and "working together effectively requires open communication" (M = 4.67, SD = 0.68). Two items related to the family or caregiver, that is, "parents should be included in the team" (M = 4.58, SD = 0.79), and "the needs of the family should be considered first" (M = 4.58, SD = 0.79), and "the needs of the family should be considered first" (M = 4.58, M = 0.79).

4.14, SD = 1.13) were rated somewhat lower but still in the high range. Overall, caregivers had a good understanding of the importance of professionals and their own roles on the team.

Two questions were asked on caregiver participation in the team. Of the total number of caregivers, 82.2% believed they were highly involved in the team and 95.3% of caregivers were highly willing to participate in the team. A Chi-square test revealed a statistically significant association between "levels of involvement" and "willingness to participate in the team". The strength of the relationship was assessed by means of the Phi coefficient, which was .291, indicating a medium effect size (Field, 2013). This implies that in practice a high level of involvement was more likely in respondents with high willingness to be involved (98%) than in those with medium or low willingness to be involved (81%).

# **Advantages of collaboration**

Ten closed-ended questions and one open-ended question were asked to determine caregivers' perception of the advantages of collaboration in ECI services. The mean scores for all items were high, ranging from 4.58 to 4.72. This implies that all the caregivers perceived collaboration to be beneficial for parents, and children. Four items received particularly high mean scores; these were in relation to "parents access[ing] the services needed" (M = 4.72, SD = 0.55), "help[ing] to provide many services effectively" (M = 4.71, SD = 0.46), "help[ing] parents to improve their abilities in taking care of their children" (M = 4.70, SD = 0.58), and "improve[ing] the quality of life of children and families" (M = 4.70, SD = 0.46). In response to the open-ended question, two out of 64 caregivers stated that collaboration improved their knowledge (1) and provided them with ideas to deal with problems (1).

# **Difficulties with collaboration**

Nine closed-ended questions and one open-ended question were asked to determine caregivers' perception of the difficulties with collaboration in ECI services. High mean

Running head: COLLABORATION WITH CAREGIVERS IN ECI SERVICES IN GAUTENG, SOUTH AFRICA scores in this domain ( $\geq$  4) imply that caregivers agreed with the item, indicating that it was a challenge for collaboration. A score of three implies that they were neutral about the item. Low mean scores ( $\leq$  2) imply that caregivers disagreed with the item, indicating that it was not a challenge for collaboration.

Overall, the results show that caregivers did not perceive challenges with collaboration. Three items, "professionals' lack of awareness of the family's culture" (M = 3.16, SD = 1.38), "professionals lack of understanding of family needs" (M = 2.95, SD = 1.30), followed by "insufficient time for collaboration" (M = 2.91, SD = 1.26) presented with means in the neutral range; however, these were higher than all other items in the domain, somewhat suggesting that caregivers may have perceived these items to be possible challenges for collaboration. The standard deviations for all items were high, implying that caregivers had a wider range of opinions on these items.

Six out of 64 caregivers responded to the open-ended question and reported that professionals do not have time to listen to what caregivers are saying (1); that there is lack of progress with the child (1); and that work commitments render it difficult for them to regularly participate in the team (2). Furthermore, caregivers indicated that assistants are required to help with the different languages (1); and that support, in terms of day-care facilities, are required for their children (1). Consistent with the wider standard deviations in this area, caregivers responded to the open-ended question in this domain, compared to the other domains, suggesting that caregivers may be experiencing various challenges with collaboration in ECI services.

#### **Factors influencing collaboration**

This domain comprises two sub-domains, namely, "organizational factors influencing collaboration" and "interpersonal factors influencing collaboration", with nine and 19 items respectively.

With respect to the "organizational factors influencing collaboration", the overall mean score was 4.44 and standard deviation was 0.52. The mean scores for all items were high, ranging from 4.34 to 4.72. High scores imply that the caregivers agreed that organizational factors were integral to successful collaboration. Three items presented with the highest mean scores; these were in relation to "sharing of resources such as equipment for child treatment" (M = 4.72, SD = 0.55), "professional expertise" (M = 4.67, SD = 0.56), and "sharing of information" (M = 4.61, SD = 0.63).

With respect to the "interpersonal factors influencing collaboration", the overall mean score was 4.56 and the standard deviation was 0.42. The mean scores for all items were high, ranging from 4.08 to 4.80, implying that the caregivers perceived all interpersonal factors to be integral to collaboration. Of these, three items received the highest mean ratings; these were related to "mutual respect" (M = 4.80, SD = 0.41), "professional's honesty to parents" (M = 4.77, SD = 0.46) and "parent participation in teamwork" (M = 4.77, SD = 0.53). Two items that were rated somewhat lower but still in the high range were "professionals do not criticize parent's decisions" (M = 4.08, SD = 0.90) and "beliefs in including families in the team providing services for young children" (M = 4.22, SD = 1.05). The latter item presented with a large standard deviation, implying that caregivers had a wider range of opinions on this item. There were no responses to the open-ended question in this domain.

## **Outcomes of collaboration**

This domain comprises three sub-domains, namely, "satisfaction with collaboration", with five items, "effects of collaboration", with seven items, and "effectiveness of collaboration", with two items.

With respect to the "satisfaction with collaboration," the mean score for this subdomain was 4.31 and the standard deviation was 0.70, with all items rated above 4 except for the item "The opportunities to interact with other families" (M = 3.91, SD = 1.15). This item Running head: COLLABORATION WITH CAREGIVERS IN ECI SERVICES IN GAUTENG, SOUTH AFRICA presented with a large standard deviation, implying that caregivers had a wider range of opinions on this item. Approximately 60% (n = 39) of caregivers were extremely satisfied with receiving the services needed and with the services provided by the team.

The mean scores for the "effects of collaboration" were high, ranging from 4.41 to 4.78, with an overall mean of 4.55 and standard deviation of 0.46. This implies that caregivers perceived the effects of collaboration in teams to be positive. Two items that were rated somewhat lower but still in the high range were with respect to "children are able to receive all services from one place" (M = 4.41, SD = 0.87) and "children feel[ing] safe because all services are provided in one place" (M = 4.42, SD = 0.75).

With respect to the "effectiveness of collaboration", the mean score was 4.56 and standard deviation was 0.57. Of the total number of caregivers (n = 64), 62.5% (n = 40) indicated that the team was "extremely effective", 29.7% (n = 19), "highly effective"; and only 1.6% (n = 1) reported that the team was "less effective." Furthermore, 65.6% (n = 42) of caregivers perceived parent-professional collaboration to be "extremely effective", 29.7% (n = 19), "highly effective"; while 1.6% (n = 1) reported that the team was "less effective."

## Relationships between collaboration and involvement

Correlation analysis was conducted for caregivers' perceptions of collaboration with their level of involvement and willingness to be involved in the team (Table 4). For correlation analysis, the items in the "effectiveness of collaboration" sub-domain were reverse scored, since the numerical scoring scale for this sub-domain was in the opposite direction to the scales in the other domains.

**Table 4.** Correlation between caregivers' perceptions of collaboration, and levels of involvement and willingness to be involved in the team

Domains	Levels of	<i>p</i> -value	Willingness to be	<i>p</i> -value
	involvement		involved in the team	
Domain 1: Understanding of	$r_s(62) = .112$	.380	$r_s(62) = .002$	.987
collaboration				
Domain 2: Advantages of collaboration	$r_s(61) = .178$	.164	$r_s(61) = .182$	.154
Domain 3: Difficulties with collaboration	$r_s(62) =366**$	.003	$r_s(62) = .010$	.937
Domain 4: Factors influencing	$r_s(62) = .000$	.999	$r_s(62) = .112$	.376
collaboration				
Domain 5: Outcomes of collaboration				
Satisfaction with collaboration	$r_s(62) = .250*$	.047	$r_s(62) =016$	.899
Effects of collaboration	$r_s(62) = .162$	.202	$r_s(62) = .018$	.885
Effectiveness of collaboration	$r_s(62) = .279*$	.025	$r_s(62) = .348**$	.005

<sup>\*</sup>p<.05, \*\*p<.01

There is a moderate negative correlation between caregivers' "levels of involvement in the team" and their perception of the "difficulties with collaboration" ( $r_s(62) = -.366$ , p = .000 < .01); higher scores on the "difficulty" domain were associated with lowest "involvement" scores, implying that caregivers who perceived greater difficulties with collaboration were less involved in the team. Furthermore, there is a weak to moderate positive correlation between caregivers' "levels of involvement in the team" and "satisfaction with collaboration" ( $r_s(62) = .250$ , p = .047 < .05) as well as caregivers' perceptions of the "effectiveness of collaboration" ( $r_s(62) = .279$ , p = .025 < .05). These correlations indicate that caregivers who were more involved in the team perceived greater satisfaction and team effectiveness. Furthermore, there is a moderate positive correlation between caregivers' "willingness to work in a team" and their perception of the "effectiveness of collaboration"

Running head: COLLABORATION WITH CAREGIVERS IN ECI SERVICES IN GAUTENG, SOUTH AFRICA  $(r_s(62) = .348, p = .005 < .01)$ , implying that caregivers who perceived high team effectiveness were more willing to work in a team.

# Relationships between advantages, difficulties, factors influencing collaboration and outcomes

The correlation between caregiver' perception of the advantages, difficulties, factors influencing collaboration, and outcomes (satisfaction, effects, and effectiveness of collaboration) is presented in Table 5.

**Table 5.** Correlation between caregivers' perceptions of advantages, difficulties, factors influencing collaboration, and outcomes (satisfaction, effects, and effectiveness) of collaboration

Domains	Satisfaction with	Effects of collaboration	Effectiveness of
	collaboration		collaboration
Advantages of	$r_s(61) = .419**$	$r_s(61) = .519**$	$r_s(61) = .334**$
collaboration	(p = .001)	(p = .000)	(p = .007)
Difficulties with	$r_s(62) =118$	$r_s(62) =107$	$r_s(62) =191$
collaboration	(p = .355)	(p = .402)	(p = .132)
Factors influencing			
collaboration			
	$r_s(62) = .182$	$r_s(62) = .395**$	$r_s(62) = .259*$
Organizational	(p = .149)	(p = .001)	(p = .039)
Interpersonal	$r_s(62) = .416**$	$r_s(62) = .593**$	$r_s(62) = .375**$
	(p = .001)	(p = .000)	(p = .002)

<sup>\*</sup>*p* < .05, \*\**p* < .01

There was a moderate positive correlation between caregivers' perceptions of the "advantages" ( $r_s(61) = .419$ , p = .001 < .01) and "interpersonal factors" ( $r_s(62) = .416$ , p = .001 < .01) with outcome measure (satisfaction). High scores on the "advantages" domain and "interpersonal factors" sub-domain are associated with high "satisfaction" scores. This

Running head: COLLABORATION WITH CAREGIVERS IN ECI SERVICES IN GAUTENG, SOUTH AFRICA implies that caregivers who were more satisfied with collaboration perceived greater

advantages and agreed more with the interpersonal factors influencing collaboration.

There was a strong positive correlation between caregivers' perceptions of the "advantages" ( $r_s(61) = .519$ , p = .000 < .01) and "interpersonal factors" ( $r_s(62) = .593$ , p = .000 < .01) with outcome measure (effects). There also was a moderate positive correlation between caregivers' perceptions of the "organisational factors" ( $r_s(62) = .395$ , p = .001 < .01) with outcome measure (effects). Overall, high scores on the "advantages" domain and "organisational factors" and "interpersonal factors" sub-domains were associated with high "effect" scores. This implies that caregivers who perceived positive effects for collaboration also perceived significant advantages and strongly agreed with the organisational and interpersonal factors influencing collaboration in teams.

There was a moderate positive correlation between caregivers' perceptions of the "advantages" ( $r_s(61) = .334$ , p = .007 < .01), "organisational factors" ( $r_s(62) = .259$ , p = .039 < .05), and "interpersonal factors" ( $r_s(62) = .375$ , p = .002 < .01) with outcome measure (effectiveness). Overall, high scores on the "advantages" domain and "organisational factors" and "interpersonal factors" sub-domains were associated with high "effectiveness" scores. This implies that caregivers who perceived high team effectiveness also perceived high advantages, and strongly agreed with the organisational and interpersonal factors influencing collaboration in teams.

# **Discussion**

The findings of this study show high positive ratings, indicating that caregivers had a good understanding of collaboration and perceived collaboration to be important and beneficial for young children and their families. Moreover, caregivers considered collaboration to be effective and were satisfied with collaboration.

Whilst caregivers acknowledged that they should be included in the team, that prioritizing family needs are important, and that decision-making should involve all team members (high positive ratings), these items were rated somewhat lower but still in the high range, in comparison to the other items in the "understanding of collaboration" domain. Caregivers felt the opinions of professionals to be important for successful caregiver-professional collaboration. The lesser importance given to their own involvement in teams by caregivers may be a reflection of the medical model approach (Rowe & Moodley, 2013) which values professionals as the experts knowing what is best for the child and family. These findings may have been confounded by caregivers having low education (Statistics South Africa, 2015), and unemployment (Rowe & Moodley, 2013). Results of this study show that 34% of caregivers had Grade 10 or lower, 59% of them had a Grade 12 education, with approximately 64% being unemployed.

The overall high rating in line with family-centered care is a welcoming finding, since it may be reflective of the changing nature of the service delivery in the healthcare system in South Africa. Since 1997, the democratic government in South Africa has promoted the concept of *Batho Pele*, a Sesotho saying which means "People First" for all public service departments (Department of Public Service and Administration, 1997). At the heart of the Batho Pele initiative are the eight key principles of consultation, service standards, redress, access, courtesy, information, transparency, and value for money. Many of these principles, for example, consultation (defined for service providers as interact with, listen and learn from the people you serve), and information (public servants are encouraged to spend some extra time with people who need a better explanation because they cannot understand) are consistent with the values inherent within family-centered care.

Caregivers in the current study were cognizant of the challenges experienced by professionals with regards to the diverse languages spoken by families, with a few

respondents suggesting the use of translation services in order to better understand professionals. Whilst all ECI services may not employ translators or interpreters, Penn (2007) reports that informal interpreters (e.g. nurses, cleaning assistants, and family members) are used in some healthcare services in South Africa. Similar to the challenges with language, some caregivers perceived that professionals were not always aware of the intricacies of their culture. This is confirmed by a study conducted by Ramklass (2009) where the findings showed that community physiotherapists had difficulties communicating across cultural barriers, and the professionals themselves suggested training in cultural competence.

Caregivers in this study perceived the importance of team members having expertise in collaborating, displaying mutual respect, having knowledge of the services available, showing commitment, and sharing information. When work is shared, team members feel valued as well as there is symmetry in power in relationships, which is indicative of a true partnership relationship (Buljac-Samardzic et al., 2011; D'Amour et al., 2005). Establishing true partnership demands time; however, caregivers in the current study had varied opinions on whether there was sufficient time for collaboration in their current ECI service.

Training in collaborative teamwork was considered essential by caregivers in the current study. The potential benefits for training in the transdisciplinary approach is considerable as it is family focussed and has shown to improve the effectiveness of services (King et al., 2009). Importantly, training in the transdisciplinary approach has been argued to be crucial in South Africa in order to make the most effective use of the limited number of health professionals trained in providing intervention to young children and their families (Samuels et al., 2012; Swanepoel, Louw, & Hugo, 2007).

The shortage of suitably trained professionals has plagued health services in public institutions in South Africa for many years (Coovadia et al., 2009). Similarly, the findings of the current study show that ECI is generally provided in healthcare settings by

Running head: COLLABORATION WITH CAREGIVERS IN ECI SERVICES IN GAUTENG, SOUTH AFRICA interdisciplinary or multidisciplinary teams, and members comprising the team can emanate from different institutions (clinic and hospital), due to the lack of specialized personnel working in one institution. Hence, caregivers may be required to attend ECI services in different settings, as affirmed by respondents in the current study who rated the item "children receiving all the services from one place"; positive but somewhat lower in comparison to other items in the domain. While caregivers in South Africa still continue to attend these services because they strongly value the voices of professionals, they also highlighted the importance of training in the collaborative approach. Central to this collaborative training for professionals in South Africa are the consideration of cultural and

## **Conclusion**

linguistic factors pertinent to families and children with disabilities.

Overall, the results showed high positive ratings and that caregivers have a good understanding of collaboration, perceived positive advantages and outcomes to collaboration, perceived it to be effective and were very satisfied with the collaboration in teams.

Resources, efficient communication, commitment, and consideration of language and cultural factors were considered to be highly important by caregivers. In relation to family-centered practices, prioritizing the needs of the family, involving all team members in decision-making, as well as including the caregiver in the team, although rated positively, was given somewhat less credence by caregivers. This may suggest that caregivers in South Africa may not comprehensively understand family-centered care.

# Limitations and recommendations for future research

The current study does present with some limitations. The limited number of sites participating in the study and the relatively small (n = 64) sample size, limits the generalizability of the results. Furthermore, the limited sample size prohibited comparison across settings (hospitals and clinics) and the ability to investigate variable relationships

Running head: COLLABORATION WITH CAREGIVERS IN ECI SERVICES IN GAUTENG, SOUTH AFRICA through factor analysis (Nunnally, 1978). Other factors influencing the generalizability of the results were that the caregivers were recruited from a specific region, that is, Pretoria in the Gauteng Province, as well as specific language.

Furthermore, caregivers were recruited from the ECI clinic on a particular day and time of the week and were thus limited to those particular participants, limiting the opportunity for identifying participants of varied characteristics and responses to the items in the measure.

Future research should focus on further reliability and validity testing of the CECI-C(R) using a larger sample of respondents. A shortened version of the CECI-C(R) could be developed, following reliability and validity testing, including factor analysis, test-retest reliability, construct validity, and concurrent validity. Qualitative research such as focus groups and in-depth interviews can provide a richer understanding of caregivers' perception of collaboration. Since ECI teams require collaboration between families and professionals, it would be valuable to gain the perspectives of professionals; therefore professionals' perspectives on collaboration in ECI teams will be the authors' next focus.

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