Family centred Early Intervention programmes in Jordan:

A grounded theory study into family and occupational therapists' collaboration

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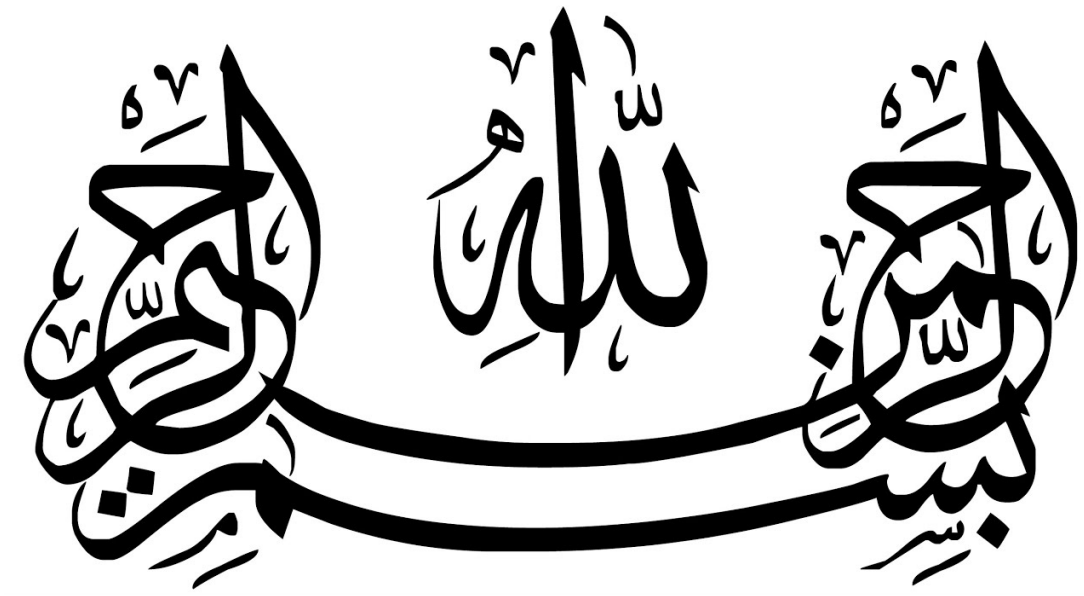

In the name of Allah the Merciful

Abstract:

This study looks into the perspectives of occupational therapists and families of children with disabilities in Jordan engaged in Early Intervention (EI) programmes. The aim of this study is to explore how EI programmes apply the family-centred approach, and specifically to investigate:

- The perspectives of families regarding their role within the intervention, and what steps were taken by OT to establish and encourage this role.
- The perspectives of OT on how they facilitate family-therapist collaboration within EI programmes.
- Generate a theory to describe parent-therapist collaboration within early intervention in Jordan.

Data were collected from multiple-sources including field notes, session observations, and interviews with experienced early intervention Jordanian occupational therapists and their clients' families, to determine the extent to which family centred model is being promoted by accessing records, observing parent-therapist meetings, and studying intervention records.

Grounded theory is used to explore the different factors influencing the process of constructing family-therapist collaboration.

Findings:

Several themes emerged from the data describing the parent-therapist

collaboration within the early intervention programme in Jordan, including: power imbalance in the parent-therapist collaboration, early intervention within the Jordanian culture, categorising parents, and language use in sessions. These themes generated the Power Scale framework, which describes the therapeutic collaboration between therapists and parents within EI programmes.

The Power Scale framework has three main elements: Knowledge, Expectations, and Engagement. Each element is described from the perspective of parents and then the therapist at the start of the collaboration, with an explanation of the relationship between these elements which changes as the collaboration progresses. The Parent-therapist collaboration in early intervention is also impacted by a variety of external factors including the cultural view and political context within which this collaboration operates. Only through understanding the elements of the parents-therapist collaboration and the external factors impacting it can we achieve a positive therapeutic relationship within the early intervention programme.

Conclusion:

The parent-therapist collaboration within the early intervention is a complex process that starts at the beginning of the intervention and develops over time. This process is influenced by internal factors including parents' and therapists' knowledge, expectations, and is reflected in their engagement. It is also impacted by external factors such as the cultural understanding of the role of health professionals, the awareness of the OT role, and the policies governing early

intervention programmes in Jordan. Although family centred model within early intervention ideally promotes a partner role for the parents with the therapist assuming a support role, the reality of early intervention programmes in Jordan reveal a compromise achieved by therapists and parents which allow for different versions of this role ranging from recipient to trainees, and depending on the internal and external factors that influence parent-therapist collaboration.

Acknowledgement:

Read: In the name of thy Lord Who createth

Those are the very first words spoken to Prophet Muhammad, making 'Read' the first command in Islam to emphasise the importance of seeking knowledge. For me this command has always guided my life, reading and acquiring knowledge to learn about life, and possibly enforce change for the best.

This thesis is dedicated to my father, who passed away one month before the start of my PhD. In his last days he wanted to make sure I will be ready to pursue my dream, he was as always encouraging and supportive of my ambition, and throughout this PhD, especially at those times when I was tired or overwhelmed, I would remember him telling me (you can do this because I prepared you to be a leader). I hope I made you proud Yaba.

My love and gratitude goes to my mother and my family who were there for me in every step of the way, even though we were miles apart, they shared my worries and stress, and so now they share my achievement. I also give my gratitude to all my friends who kept up an endless stream of encouragement and positive thinking, and helped me visualise my goal so I can maintain my motivation.

My gratitude goes to all my supervisors, those who supported me at the start of the PhD; Dr Wendy Bryant and Dr Mark Francis-Wright, but had to leave, as well as my supervisors at a later stage Dr Gillian Green and Dr Peter Martin.

I also thank my PhD comrade Ellen Adomako, I thought a PhD would be lonely but her friendship and support made it an enjoyable journey. And I thank the Occupational therapy team at the University of Essex who gave me their advice and support whenever I needed.

Finally, I thank my sponsors at the Hashemite University who made it possible for me to pursue this PhD.

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1. Chapter one: Introduction:

This thesis will describe the study titled (Family centred Early Intervention programmes in Jordan: a grounded theory study into family and occupational therapists' collaboration) which was conducted within a PhD programme in Occupational therapy, and began in January 2016.

The aim of this study was to explore how early intervention programmes use the family-centred model within Jordan, and specifically to:

1. Understand the perspectives of families regarding their role within the intervention, and what steps were taken by occupational therapists to establish and encourage this role.
2. Explore the perspectives of occupational therapists on how they facilitate family-therapist collaboration within early intervention programmes.
3. Generate a theory to describe parent-therapist collaboration within early intervention in Jordan.

1.1. Introduction to the research:

Family centred services are defined as a group of philosophies and approaches to care for children with special needs, with the recognition that family is the constant in the child's life, and thus partnership between the family and health professionals is the foundation for these services. Family centred services are based on three premises: 1) parents are the experts of their child and they know them best. 2) each family is unique. 3) a supportive family and community context ensures the

child's optimal functioning (Rosenbaum et al. 1998).

The use of Family centred services within paediatric rehabilitation is well established within literature, and is supported as best practice (Hanna and Rodger, 2002, Novak and Honan, 2019, Rodger and Kennedy-Behr, 2017). One of the main areas where a family centred model seems to dominate are early intervention programmes, where the family as a unit requires support to facilitate their child's development, thus moving the focus of the services from the child to the family as a whole.

Early intervention programmes EI are services provided for infants or toddlers younger than 3 years old. These services target children who are diagnosed with physical or mental conditions, or children who are at risk of developmental delays; including physical, cognitive, social-emotional, communication, or adaptive delays (Hanna and Rodger, 2002, Wagenfeld and Kaldenberg, 2005, Case-Smith and O'Brien, 2013, Ertem and WHO, 2012). EI services are presented within a team of professionals that may include occupational therapists, physiotherapists, special education specialists, and speech and language pathologists. Services are provided within the child's natural environment to promote participation within the home and community, however; EI could include some services that are clinic-based (Hanna and Rodger, 2002; Case-Smith and O'Brien, 2013).

Occupational therapists' role within EI include; investigating all the different aspects affecting the child's development, examining closely family interaction and routines, providing guidelines for the family to overcome/deal with obstacles

affecting the child's normal development, as well as supporting the family to enhance their capacities to care for the child's health and development, within the families daily routines and natural environment (Rodger, 2013, Wagenfeld and Kaldenberg, 2005).

A key element to achieve the full role of Occupational therapy in EI is building and maintaining a supportive collaboration with the family, one that will encourage open communication, and provide the required base for cooperation. Literature in the field of EI supports the importance of establishing such a collaboration, by advocating the use of specific positive attitudes that were found to enhance family-professional collaboration (Hanna and Rodger, 2002).

The use of a family centred model within EI programmes is recommended in the literature as best practice, however; implementing this model is reported to face several challenges, and relevant literature reveals discrepancies in the views of therapists and families towards this model (Hanna and Rodger, 2002, Rodger and Kennedy-Behr, 2017, Coyne, 2015, Darrah et al., 2012).

This research examines how professionals and families collaborate within early intervention programmes in Jordan, and aims to shed some light on the application of the family centred model within this Eastern culture, which would help in evaluating the quality of this type of paediatric services, and hopefully provide the rehabilitation field and policy makers in Jordan with some suggestions to improve these services.

1.2. Motivation behind the research:

Occupational therapy as a profession is relatively new in Jordan, the first group of occupational therapists to graduate with a diploma in OT was in 1992, and most of them mainly worked within public and military hospitals. Thus, the need to train more therapists and start occupational therapy programmes within private and non-governmental settings lead to the establishment of three BSc programmes at local universities in 1999, which helped expand the work of occupational therapists around the country (Tariah et al., 2011, Darawsheh, 2018). I have graduated in 2003 from the first occupational therapy BSc programme running at the University of Jordan, this meant that I was among the first cohort of BSc qualified occupational therapists in my country, and thus began my work with the aim of helping to establish a strong foundation for my profession. My work in paediatric occupational therapy began at a non-governmental organisation called Al Hussein Society, it included three different programmes; the early intervention, the school, and the community based rehabilitation CBR team. The role of occupational therapy was already established in this centre by volunteers from European countries, who helped in setting up the early intervention programme in 2000, and setting the standards for OT work based on their experiences within their countries.

As a Jordanian occupational therapist I shared the same language and cultural background with the clients, which gave me a different perspective into the challenges that the team faced on a daily basis, and provided me with many

opportunities to work with Jordanian families and help them to support their children. My work focused on re-enforcing the role of occupational therapy within the three different programmes, and implementing the intervention models I have learned in my training as an OT. At that time the EI programme was set following a design adapted from the United Kingdom through the consultation of a specialised UK physiotherapist, and the principles of family centred practice were used. As a senior occupational therapist I was leading the team working at the three different programmes; EI, school, and CBR, and we as a team were facing difficulties in running the EI programme, particularly in using family centred model with our clients, who were not participating in the intervention as we have anticipated.

The management of the centre decided to evaluate the EI programme in 2009 by inviting the same physiotherapist who established it to review the policies and procedures, this evaluation was conducted through observations and interviews with parents and therapists over a period of two weeks, I had the chance to shadow the evaluating consultant and to gain a full picture of the programme from the perspectives of parents and therapists. The findings from this evaluation concluded with a description of a child centred EI programme rather than a family centred one, the recommendations focused on enhancing the role of the parents through providing them with information and involving them in the sessions, as well as communicating with the parents constantly and using Arabic language to ensure their engagement. During my study I was given access to this report as part of the early intervention records and collected notes on the recommendation.

The main challenges we faced as a team within the EI programme revolved around defining the role of the parents within the intervention, and encouraging them to assume this role, as well as organising the programme to facilitate cooperation between the team and families. The difficulties we faced in improving the programme to meet our vision involved different parties. The regulations within the centre did not encourage partnership with the families but rather placed the staff as the main authority, an example for this is the scheduling of sessions which was based solely on the therapists' weekly schedules, while parents were informed of the available appointments and were expected to meet these appointments. At the same time we faced resistance from the families to assume a more active role in their children's intervention, and frequently had parents who did not want to learn during the sessions and insisted on letting the therapists do the session.

This experience formed the basis for my current research, I have worked with families who wanted to help their child, and although I had the same goal as a therapist, but we seemed to work separately towards that goal, this made me wonder about the best way to build a positive collaboration with the parents. The process of evaluating the EI programme helped me hear the views of parents and therapists, which gave me an insight on the difference in the perspectives of those two groups. I became curious to understand the relationship between therapists and parents within the EI programme; I wanted to know how this relationship could potentially lead to a collaboration that helps the family in dealing with the child's problems. As a paediatric occupational therapist I strongly believe in the role the family plays in their child's intervention, and by unpacking the therapeutic

relationship between the therapist and the family I aimed to understand how a therapist could successfully help the family achieve this role.

My motivation remains to support the occupational therapy profession in Jordan, by studying the needs of therapists and clients, then help in setting clinical standards for OT work based on the specific requirements of the Jordanian community. It is my belief that each community has their own unique set of needs and contextual factors, which should be investigated using research to support professionals in meeting these needs. I find it rather naïve to expect all humans around the world to react similarly to health problems and therapeutic interventions, when there are so many variations of human experiences and communities, and diverse cultural understandings of health and therapy. My clinical experience showed me the diversity in human needs even when people share the same cultural background, and this has directed my thinking as a therapist to listen to my client before I form any picture of their needs or intervention. Similarly, I am attempting in this study to listen to the therapists and clients in Jordan before I form any assumption regarding their needs, then use their voices to describe what they face and ultimately what they need from an occupational therapy programme.

1.3. Jordan as the context:

Jordan, officially the Hashemite kingdom of Jordan, is an Arab nation located on the east bank of the Jordan River, and is at the midst of politically active surroundings including borders with Syria on the north, Palestine on the east, Iraq on the west,

and Saudi Arabia on the south. Jordan is approximately 60,000 square miles and is located in the heart of the Middle East, which gives it a centralised geographical location that served historically as the crossroad between Asia, Africa, and Europe, thus connecting the East and West, which gave it a great role as a conduit for trade and communications, a role that continues to this day. Jordan is a land steeped in history, having been part of the world's greatest civilisations including the Sumerian, Akkadian, Babylonian, Assyrian and Mesopotamian Empires from the East, Pharaonic Egypt from the West, and the nomadic Nabateans who built their empire in Jordan after migrating from the south of the Arabian Peninsula. Jordan was also incorporated into the classical civilizations of Greece, Rome and Persia, the relics of which are scattered across the Jordanian landscape (King Hussein Organisation, 2001).

The population of Jordan according to the latest statistics is estimated at 9.9 million (The World Bank, 2019), with about 2.9 million as non-citizens which include refugees, legal, or illegal immigrants. Jordan was named the largest refugee hosting country per capita in the world in 2016, with refugees from Palestine, Syria, and Iraq mainly. 98% of the Jordanian population share a common Levantine Sematic ancestry, and the remaining 2% are from different ethnic minorities including Armenian, Cercassian or Chechens. The country's dominant religion is Islam, with only 6% of the population as Christians, and Arabic is the official language with English as the second most widely spoken language. The average age of the population is 22.5 years, with 67.78% below the age of 30, and 25.34% below the age of 9 years (WPV, 2019).

The capital and largest city of Jordan is Amman, with a population of about 1.5 million people. Amman is one of the world's oldest continuously inhabited cities and one of the most liberal in the Arab world, it holds the biggest governmental agencies and is the economical centre in the country. There are 11 other cities in Jordan with smaller populations ranging from 700,000- 32,000 and with Amman are the home for 85% of the total population, making Jordan an urban country (The World Bank, 2019).

Due to the young demographic of the Jordanian population, and a cultural emphasis given to education as a core value in the community, education is considered a main focus of the government and is allocated a high proportion of the public budget spending annually, this has resulted in a literacy rate of 98.01% in 2015 which is one of the highest in the world. The structure of the educational system in Jordan includes formal and non-formal systems, starting at the age of 3 years the non-formal system of pre-schooling includes private and public kindergarten centers, followed by ten years of compulsory basic education following government run curricula, and two years of secondary academic or vocational education which lead to a General Certificate of Secondary Education Exam. Higher education in Jordan is provided by public and private universities and colleges within the different cities of the country, about 2.5% of the total population are enrolled in universities, and the Ministry of Higher Education governs the quality and various regulations related to this sector.

Jordan shares similar Arabic and Islamic cultural background with other Middle Eastern countries, however; with the Bedouin background of most of the major

families or tribes in the country, as well as the influence this background had while the constitution and laws within the country were written, the Bedouin culture has a clear influence on the lives of Jordanians. These are seen through the emphasis given to the family name and honor which impacts where people live or what career choices they are more likely to follow, for example; political and military careers are very common among descendants from large influential tribes, who encourage their children to study law or join the army and take pride in such careers.

The cultural view towards health and medicine is derived from Islamic principles mainly, where good health is achieved through a sound body, mind, and spirit. The Islamic belief dominant in Jordan is that for every illness there is a cure, and it is the responsibility of the individual to seek a cure for whatever illness they are suffering (Hasnain et al., 2008). This is derived from the words of Prophet Mohammad:

'Make use of medical treatment, for Allah has not made a disease without appointing a remedy for it, with the exception of one disease, namely old age. (Abu-Dawud, n.d., no. 3855)

The role of the family in the pursuit of cure is evident, as members of the family support the sick individual with care as needed, and ensure they are helped in all their daily needs. Individuals with disabilities are perceived as sick and thus entitled to be cared and supported by the family, this care is perceived socially as duty, and is also rewarded by Allah as a selfless good deed. The community expects the family (including the extended and the tribe) to provide the care needed for the

sick individual, and to support them in all their needs for as long as they live (Al-Aoufi 2012).

Disability in Jordan:

In 2015 a national Jordanian census declared the percentage of persons with disabilities in Jordan to be 11.5% of the population, however this census did not include children under the age of 5 years, and accordingly the percentage did not accurately reflect the prevalence of disability in Jordan. In 2016 the Higher council for the affairs of persons with disabilities HCD in Jordan officially stated the percentage of persons with disability in Jordan to be estimated as 13%. This remains the official number to represent the prevalence of disability in Jordan, however it is based on an estimation in accordance with the World Health Organisation WHO numbers. Physical disabilities are estimated to be the most common type in Jordan with 17.3 percent of the total, followed by vision loss at 16.2% (Thompson 2018).

While the national legislation and political efforts in Jordan show a genuine drive to ensure the rights of persons with disabilities (Buchy et al 2017), several challenges are reported to the equal participation of Jordanians with disabilities in the community, including negative attitudes within some local communities, and a stigma associated with disabilities in general, but more obvious with intellectual and hereditary types, resulting sometimes in families' efforts to hide individuals with disabilities away from the rest of the community (Jalal and Gabel 2014; Al-Zboon & Hatmal 2016).

The reasons for this stigma are linked mainly to lack of knowledge, superstitious beliefs, and in some situations health related misconceptions. However, studies also show a change of attitude to a more positive perspective in Jordan regarding disability, as people tend to attribute the cause of disability to God's will and biomedical causes, which results in them seeking health professionals (Al-Dababneh, Al-Zboon & Baibers 2017).

The main laws related to persons with disabilities in Jordan are: the Law of Disabled people care (1993), Law on the rights of persons with disabilities (2007) and Law on the rights of persons with disabilities (2017) (HCD, 2019). Additionally, Jordan had ratified the Convention on the Rights of Persons with Disabilities (CRPD) in 2008 which resulted in the establishment of the Higher council for the affairs of persons with disabilities HCD.

While currently the situation of disability is based on estimations in terms of numbers, and few studies discuss laws and attitudes, it is clear there is an urgent need to conduct a thorough and comprehensive survey to identify the scale, type, nature and prevalence of disability, as well as more studies to identify the changes in attitudes and cultural norms regarding disabilities in Jordan (Thompson 2018).

1.3.1. **Occupational therapy in Jordan:**

The first educational programme for occupational therapy in Jordan began in the Royal medical services (1989-1997), this three years diploma programme aimed to train occupational therapists to source the military medical services primarily.

However; it has also established the occupational therapy profession in the country, and was the second educational programme in the Middle East for the profession (AlHeresh & Nikopoulos, 2011). In 1999 the Diploma programme was developed into a Bachelor's degree at three public universities within the three biggest cities in Jordan, which expanded the number of graduates annually (Tariah et al., 2011). The educational curricula for occupational therapy at the three universities is delivered in English, and is based on the curricula of different universities in the UK, Canada, and the USA including (University of Pittsburgh, Brunel University, McGill University, and University of Kentucky) (UoJ, 2017). These programmes were led mostly by foreign teachers until the first group of Jordanian Master's degree and PhD holders returned in 2007 (Tariah et al., 2011).

The educational OT curricula used within the three universities in Jordan adopt a medical model, with the first two years dedicated for modules such as biology, physics, physiology, anatomy, internal medicine, surgery, neurology, and biomechanics. This is followed with two years of OT specific modules that are divided into three main streams: Physical dysfunction, paediatrics, and mental health. An overview of the curricula shows the emphasis given to medical diagnosis and interventions as opposed to a social perspective in OT. However, it is important to highlight here that these curricula have undergone few changes recently and plans are being made to update them to meet the demands of the profession. At the same time these curricula are designed to meet the requirements of the Ministry of Higher education in Jordan, which dictates the inclusion of medically based modules for all allied health educational programmes (UoJ, 2017).

The OT education in the three Jordanian universities includes several practice placement opportunities, ranging within the three main streams of paediatric, physical dysfunctions, and mental health. The placements are designed to allow students to practice OT core skills including but not limited to: interviewing clients, designing and planning intervention goals, collaborating with other health professionals, and occupation focused practice. However, with challenges faced by practicing therapists to work within international standards such as the World Federation of Occupational Therapists WFOT practice standards, while establishing a solid foundation for the profession in Jordan, the application and practice of OT core skills by OT students within placements is often unclear and limited due to health settings' system and limited resources.

Since 2003, about 800 occupational therapists graduated from the three Jordanian universities and are currently working either in Jordan or in other countries worldwide. Less than 250 are still working in Jordan according to the Jordanian Society for Occupational Therapy JSOT (JSOT, 2018), with only 8% of them with higher education degrees (Tariah et al., 2011). Occupational therapists work within three main sectors, the public health sector which includes public hospitals and centres, the military sector which is part of the army services and include working at hospitals, and the private sector which includes non-governmental organizations and private hospitals and centres.

Based on a survey conducted by Tariah et al (2011), 29% of the occupational therapists in Jordan are specialised in paediatrics, this includes therapists who work within centres or schools. However, this survey did not specify the type of

paediatric services, thus; there is no estimation of the number of OTs specialised in early intervention.

The Jordanian Society of Occupational Therapy (JSOT) is the main body promoting awareness regarding the profession, despite the limited influence this society has within the political system due to its status as a non-governmental organisation, it has helped in supporting the local universities to achieve accreditation from the World federation of Occupational therapists WFOT, and succeeded in implementing a licensing system within the Ministry of Health for practicing occupational therapists (Darawsheh, 2018). The Ministry of Health is the official institution responsible for issuing policies related to health professions, and within their policies the occupational therapy profession is linked to the physical therapy profession in terms of policies and accreditation.

1.3.2. **Early Intervention in Jordan:**

The Higher council for the affairs of persons with disabilities HCD lists 52 centres in Jordan who offer EI services, 28 of those centres are located in the capital Amman, the majority (61%) of these centres are private meaning that families pay fees for service, and 17% are governmental which provide free services and 22% are based on volunteer organisation. It is noted though that this list is based only on the centres' description of EI services, since there are no formal definition of the early intervention in Jordan within the policies or regulation of the HCD, these services could be simply categories based on the age group rather than the type of programme (HCD, 2019).

The regulatory bodies in Jordan (the Ministry of Health and the Higher council for the affairs of persons with disabilities) refer to the Early Intervention programmes within the rehabilitation policies, however; there is no definition for these programmes, the only references to a specific set of programmes is when the HCD refers to the Portage programme. It is noted however that the regulations do not include any explanation of what is meant by a Portage programme, nor any criteria to monitor these programmes.

In an effort to explain the policies governing EI in Jordan I will attempt to give a summary of the Portage programme in general. The National Portage Association in the UK describes the Portage programme as a home-visiting programme, which aims to help parents of children with special educational needs and disabilities SEND (The National Portage Association in the UK, 2019). This programme was developed in Wisconsin USA, and in 1976 was introduced in the UK to be later developed and used in different areas of the country (Russell, 2007). The model used in Portage is focused on three main elements: 1) family focus where time is spent to address the priorities of the family, 2) structured teaching which is based on the portage small steps approach, and 3) child-led play where observation of self-initiated play is done (Russell, 2007).

These key elements are somewhat similar to the Early Intervention described by Dunst (Dunst and Trivette, 1987), and does consider the family unit as the recipient of the services. However, the Portage programme is described more from an educational perspective, and the policies in Jordan also refer to this programme as a pre-school educational programme, with an emphasis on the role of special

education practitioners. Although a few centres in Jordan are adopting the Portage programme, which is typically led by a team of special education teachers and in some instances occupational therapists, the role of Occupational therapy is not clear or even mentioned within the Jordanian policies, which could be an explanation as to why this specific programme is not included within the Jordanian society for Occupational Therapy JSOT (JSOT, 2018). On the other hand, the Higher council for the affairs of persons with disabilities in Jordan does provide funding for children using the Portage programme, this is in fact part of the referral process to an EI centre and is used mainly for children with cognitive and educational difficulties (HCD, 2019).

This confusion evident in the Jordanian policies impacts directly on the Early Intervention services, with two separate regulatory bodies (the Ministry of health and the HCD) in charge of setting policies and monitoring the quality of rehabilitation services, the service providers and professional bodies (e,g. JSOT), as well as the parents of children with disabilities, have to manoeuvre through different sets of policies, where referral and complaint procedures are unclear. Another effect of this confusion I faced when designing and conducting this research was the lack of one clear definition of Early Intervention services in Jordan, and I was surprised when I started the first phase of the research in one of the largest centres in the country, that for the early intervention programme this centre had their own set of policies.

The only document I could find to include a definition for the early intervention

programmers in Jordan came from the Higher council for the affairs of persons with disabilities HCD, which is responsible for designing monitoring regulations, as well as conducting studies to evaluate the quality of services in Jordan related to persons with disabilities. In the past 5 years the HCD conducted a study specific to evaluating the early intervention programmes in the country, which was defined as educational and rehabilitation programmes targeting children aged 2 to 5 years (HCD, 2019). The study was published in 2016 within the HCD website and produced results to indicate the need for developing monitoring standards for such programmes. There is a second study to evaluate the changes made to improve the quality of early intervention programmes in Jordan, this study started in 2018 but is still ongoing.

The main focus of both studies is to evaluate the early intervention programmes in Jordan, however these programmes are described as educational and rehabilitation services offered for children between the ages of 2 years and 5 years, a description that differs from the World Health Organization WHO definition which defines EI programmes as services provided for children from birth up to three years old (Ertem and WHO, 2012). This fundamental difference interferes with the scope of the study and the results, since the participating centres did not necessarily provide services for children below the age of 2 years, and thus the formally acknowledged definition of the early intervention in Jordan is differing from the general definition in the world. However, it is worth mentioning here that the centre where my study was conducted adopts the definition of EI published by the world health organisation.

In the study conducted by HCD in 2016 the researchers contacted all the rehabilitation centres in Jordan which are 289 centres to request their participation in the study, 260 centres agreed to participate. Only 64 centres claim to provide EI services (24.23%), and the geographical distribution of these centres showed that 38 of these centres (59.4%) are located in the capital city of Amman alone. One of the main findings of the study described the currently available EI programmes in Jordan, (59.38%) of the programmes provide one or more of the rehabilitation services such as physiotherapy, occupational therapy, or speech therapy, (40%) of the centres include occupational therapy as one of the services provided. On the other hand, the study does not describe which type of EI approach is being used more in Jordan be it family centred EI, home based EI, centre based EI, or other approaches (HCD, 2019).

Another important result of the HCD study focused on the lack of standards nationwide that govern EI programmes, thus leaving each centre to come up with their own set of standards and policies, this resulted in variances between the centres, as well as adopting different approaches or models. The study emphasized the need to produce EI policies and standards to ensure good quality of services within the EI programmes. The study also highlighted the importance of including occupational therapy as one of the services provided within EI programmes. According to the study occupational therapy was found in only 40% of the centres, which is described in the study as a gap in the programme and the rehabilitation team work. The HCD study also evaluated the EI team work at the centres as (good), and concluded the importance of improving this level of quality by

promoting advanced training for the EI specialists, as well as including recommendations to the Universities in Jordan to adjust their curricula to meet the needs of the Jordanian market.

The study continued to emphasise the importance for producing specialists in the EI field from different professions, highlighting the need to provide advanced level training in family centred model and other approaches in EI. The results also showed more emphasis in the rehabilitation programmes on the child rather than the family as a whole, which resulted in limiting the impact of the EI programmes within the centres, and not using community resources available. The final recommendation from this study focused on conducting research in the EI field to ensure the development of policies and standards based on scientific methods, especially in relation to applying family centred approach, and promoting multi-disciplinary team work.

In a recent study conducted by Jordanian researchers Malkawi et al. (2020 in press) to explore the characteristics of EI programmes in Jordan from the perspectives of both occupational therapists and physiotherapists, 97 participants were recruited to complete a survey aiming to understand the current picture of EI in Jordan. While this study is still in press (Malkawi et al. 2020) it is useful in shedding some light on the challenges both OT and physiotherapists face within EI programmes.

The results of this study indicate a clear confusion in the design of the EI programmes in Jordan, with participants reporting working with children from birth up to 6 years within hospitals, centres, and schools. Only 66.5% reported starting

the intervention at an early age of below 3 years, and 78.4% reported providing parents with home programmes to follow up with the intervention. However, this study did not look into the training provided for parents to use such home programmes, or clarify the level of involvement of parents within the EI programmes. The variations in the design of EI programmes coincides with the lack of clear regulations or standards for EI work in Jordan, which is seen as a challenge to the delivery of family centred EI programmes in Jordan.

1.3.3. **Family centred Model in Jordan:**

Within health services in Jordan the traditional medical model with its "expert" authority is still dominant (Almasri et al., 2014), families are inclined to expect the professionals to make the decisions and provide "hands-on" interventions, while they take a more passive role in the intervention. On the other hand; the academic programmes in occupational therapy in Jordan provide theoretical descriptions of the different models used within the profession, including the family centred model (UoJ, 2017), however, clinical placements are conducted within the available occupational therapy settings which still lean towards the medical model.

In a study by Almasri, Saleh et al (2014), researchers examined family support systems available in Jordan from the perspective of physiotherapy, by interviewing parents of 115 children with cerebral palsy CP who were receiving services at different settings, using an Arabic version of the Family Support Scale FSS. Results indicated that parents found early childhood intervention programmes to be the least helpful services available, and researchers concluded that a traditional

medical model is still being used within rehabilitation services. Almasri et al (2014) also noted the absence of family based programmes within paediatric rehabilitation services, which results in a gap between families and rehabilitation professionals. These findings encouraged the researchers to call for more communication between families and therapists, as well as a move to empower families by adopting more family centred models.

It is possible that the change from the traditional medical model towards a family-centred model is still at its beginnings in Jordan. Although health professionals, especially occupational therapists, learn and adopt the philosophy of client-centeredness within their academic education, the implementation of these models of practice clinical remains unclear. The findings from Almasri et al (2014) indicate a need to develop regulations that promote family centred practices, especially since families who participated in the study showed an awareness of their need for support that extends beyond traditional sessions towards establishing parents' groups and social clubs, which in itself is an indication that families are in need for family empowerment practices.

Looking back at my own practice as an EI therapist, I can see a gap between what is described as typical EI in the literature and what is happening in reality in Jordan. According to Hanna and Rodger (2002) in an ideal EI programme, families are typically encouraged to take a more active role in their child's rehabilitation, this in itself poses a conflict with the more dominant "expert authority" model in Jordan. Furthermore; in Jordan, decisions regarding the intervention goals and methods, as

well as the frequency and location of sessions is usually up to the therapist not the family, although therapists do consult with the family, but the final decisions are made by the therapists.

As for the methods, location, and frequency of intervention sessions, EI therapists are encouraged to use the natural environment of the child to conduct intervention (Hanna and Rodger, 2002). Families are expected to be trained on how to help their child throughout the daily routines of the family, which entails that the family should decide upon the frequency of the sessions. In the actual application of EI programmes in Jordan, the therapist is the one who decides how, when, and where the intervention would take place. Most of the intervention is given within the clinical setting rather than the home environment, and families are expected to show up at specific times with the child for these sessions. This service resembles what Lawlor & Mattingly (1998a) have termed as “clinic culture”; where occupational therapists function within the “therapist is the expert” philosophy, and thus collaboration with the families is seen as less important than providing hands-on sessions by the therapists.

The family centred model emphasises the importance of looking at the family as a whole, and investigating the interaction style of the family as well as their daily routines, all of which are part of the services provided for the child and family, and are essential aspects which will influence the success of the intervention (Case-Smith and O'Brien, 2013). It is however unclear whether these aspects are being implemented within EI programmes in Jordan, or a more child-centred model is still

being used.

1.4. Preliminary literature review:

Prior to the start of this study I prepared the proposal for my PhD research. This included a short literature review on the main area of family centred early intervention, some of the theoretical concepts related to this research were reviewed, and the proposed methodological approach was planned. This will be presented here under the introduction section to provide an overview of the background theories and extant concepts which were used to design the study. This section will begin with a brief description of the early Intervention EI approach as a new paradigm within paediatric rehabilitation, followed by a description of early Intervention in Jordan. The Family centred model will also be discussed briefly.

1.4.1. The Conceptualization of a new paradigm in early intervention:

Early intervention is defined by Dunst (Dunst, 1985) as the “provision of support to families of infants and young children from members of informal and formal social support network, members that impact both directly and indirectly upon parent, family, and child functioning” (Dunst, 1985, p. 179). What distinguishes this definition is the distinction between formal and informal social support. Dunst considered the formal support to include the informative, emotional, and physical support provided by formal agencies such as the early intervention programmes,

while informal support included families, friends, neighbours, or other community members who provided different but equally important support for the family.

A support-based philosophy is considered a pillar within early intervention (McWilliam and Scott, 2001), one that is believed to enable professionals to understand the intricate nature of family-professional collaboration, and thus adapt practices that provide both formal and informal support for the families, in an effort to empower them to assume their natural role as leaders of the intervention process (Dunst, 2000). Family-professional collaboration is an essential part of the early intervention system, its importance is based on the support-based philosophy, which highlights the impact a positive support has on the families' ability to prioritize and focus on their child's wellbeing (Blue-Banning et al, 2004). Specifically; the types of support that is offered to the family which would empower them to participate actively in their child's development, thus; achieving the aim of a successful early intervention which is to empower the family to take their full role as the child's support.

To understand the family-professional collaboration we need to consider the types of support that the families receive within the early intervention. Based on the social network theory, one could examine support by looking into different theories that collectively form the foundation for understanding both family-professional and parent-child relationship (Dunst, 2000), the social support theory looks into both formal and informal support provided for the family (Dunst, 2000, Dunst et al., 1990), based on the notion that families with stronger support have better access

to a variety of resources, which will promote better wellbeing and health for the whole family (Keller and Honig, 2004).

The family systems theory associates the family wellbeing with its members' wellbeing (Whitchurch and Constantine, 2009) and concludes that if one or more members of the family are experiencing difficulties, the overall wellbeing of the family will be affected, which explains the kind of difficulties the family of a child with disabilities undergoes, as a direct result of this child's disability (Barnett et al., 2003).

The parent-child interaction is highlighted in the transactional theory as having an essential impact on the development and progress of the child (Mahoney et al., 1998, Mahoney and Powell, 1988). Thus, studies in this area (Mahoney and Perales, 2003, Mahoney and Perales, 2005, Barnett et al., 2003) have been looking into how professionals need to influence this parent-child relationship in a positive way, thus providing the whole family with the kind of support that will affect the child's development.

The help-giving theory in early intervention promotes supporting the family to achieve their potential (Dempsey and Dunst, 2004, Trivette et al., 1996), by helping them use their strength to become independent, using practices that support the family to learn new skills and competencies. Research in this area has shown that when families received positive help-giving practices they became more confident in attending to their needs, and were empowered to take on a more active role in their child's intervention (Dunst and Dempsey, 2007, Dempsey and Dunst, 2004,

Almasri et al., 2018).

More research was conducted to understand the influence of both formal and informal social support (McWilliam and Scott, 2001, Affleck et al., 1989, Dunst, 1985, Dunst, 2000), which resulted in a very intriguing finding. By looking into the views of families on what they considered to be the most helpful support, findings (Dunst, 2000) indicated that families perceived the EI practitioners who approached them in an informal manner to be close to the family, and valued them as highly beneficial, while EI practitioners who assumed a more formal support were viewed as less helpful.

This particular finding lead researchers to investigate the different help-giving practices that EI practitioners assume with the families, Dunst (1985, Dunst and Trivette, 1987) proposed a framework to explain the factors influencing the family-professional collaboration, particularly the help-giving styles that the professionals use when collaborating with the family. They discussed two main practices used by the professionals to empower the families; the participatory help-giving practices, and the relational help-giving practices. In an attempt to understand which kind of practices empower the families, and which have a less than ideal effect. Researchers such as (Dunst et al., 2002) used this framework to investigate the different practices used by EI practitioners from the perspectives of both families and practitioners.

In their study Dunst, Boyd et al. (2002) used their help-giving practices scale to study the relationship between help-giving practices and the different types of

family oriented models identified at 22 different early childhood programmes. Their findings suggested a strong link between positive help-giving practices and programmes using family centred model. In fact the study reinforced the importance of using help-giving practices within early intervention, thus; pointing to one way of ensuring that a programme is in fact family-centred, which is by using relational and participatory help-giving practices.

Dunst, Boyd et al (2002) described the participatory help-giving practices to include the activities that the professionals use to assist the families in strengthening their skills, and to include them more actively in the decision making process. The relational help-giving practices are related more to the behaviours of the professionals that demonstrate empathy and active listening, and would be perceived by the families as encouraging and motivating.

Research focused on studying these two help-giving styles showed positive effects on the empowerment of families, and consequently on the family-professional collaboration. Specifically; several studies concluded the importance that families attribute to the relational help-giving practices, as they view these practices as very positive and helpful (Hanna and Rodger, 2002, Dempsey and Dunst, 2004, Dunst and Dempsey, 2007). While empirical evidence established that the participatory help-giving practices are essential in the implementation of family centred care, there is evidence to suggest a less than ideal application of the family centred care policies, particularly; in professionals' use of practices that promote empowerment as suggested by Dunst (Dunst, 1985). This has been a controversial topic among

researchers who are finding conflicting results when looking into the actual use of family centred care policies (Hanna and Rodger, 2002).

In a research study aiming to investigate the actual application of family centred services by occupational therapists in the United States of America, Edwards, Millard et al (2003) interviewed six families and four occupational therapists to identify factors that encourage or hinder the use of family centred services in occupational therapy interventions. Although participants agreed on the importance of help-giving or empowerment practices used by the practitioners, one family explained that the empowerment was a result of the family's motivation rather than the occupational therapist's practices (Edwards et al., 2003). One major theme resulting in this study is the family individuality, were families discussed the importance of adjusting practices and communication within the EI to fit with the individuality of the family. This led to the conclusion that help-giving practices should be individually adjusted to fit with each families' communication style, in order for these practices to achieve its goal of empowering the family (Edwards et al., 2003).

In their review of the literature concerning processes and outcomes of family centred model, Dempsey and Keen (2008) noticed a significant difference between family and practitioners' ratings of the use of the model within Early intervention. Several studies have also found similar results (Dunst et al., 2014, Klein and Chen, 2008, Roggman et al., 2010). By looking into the actual involvement of families in their children's intervention, research suggests a link between the location of the

intervention (whether it is at the clinic or the natural environment of the child) and the active involvement of the families in the intervention. These findings clarify that when intervention is carried out at the clinic, the families tend to take a passive role of observing rather than doing the intervention, on the other hand; when intervention is carried out at the home of the child, families tend to be more active in this intervention (Dunst et al., 2014, Klein and Chen, 2008, Roggman et al., 2010).

1.4.2. **Family-Centred Model within Early Intervention:**

1.4.2.1. Routine based vs. participation based services:

There are several approaches being used in EI that were discussed throughout the literature; routine-based intervention, family guided routine-based intervention, activity-based intervention, learning opportunities, and participation-based services (Campbell and Sawyer, 2007).

While the natural environment holds an essential role in the implementation of the EI services, the use of this environment has expanded from merely the physical aspects of the home or nursery, towards the spatial aspects such as daily routines and family activities. This movement expanded the role of the family from merely assisting in planning and implementing interventions, to becoming the leader of the service, as families have the best knowledge of the child's daily routines and natural environment (Sawyer and Campbell, 2009). The early intervention practitioners' role has consequently moved towards a more supervisory or teaching aspect. This kind of collaboration is perceived as the cornerstone of the EI services

adopting family centred model.

When examining the transition from child centred care to a more family centred focus, one could observe a gradual understanding of the importance of the family role in the success of the intervention, an understanding that was based on research within the family-professional collaboration (Dunst, 2000, Hanna and Rodger, 2002, Dempsey and Dunst, 2004). Several leaders in the health field advocated for a more active role of the families, coupled with a stronger focus on the role of the professionals as teachers or "coaches". This movement lead to changes in policies governing the early intervention work in the USA (CODE and ACT, 2000) and Australia, which have also generated a need for research to examine closely the possible influencing factors that promote a successful family-professional collaboration.

Researchers in the area of early intervention advocate for using the natural environment of the child which includes home and community as the best context for the early intervention (Campbell and Sawyer, 2007, Dunst, 2002, Hanna and Rodger, 2002). This opinion highlights the importance of allowing the child to develop within their daily routines, which will include activities based on the family routines as well as community activities that enhance both intentional learning or incidental learning experiences.

This view was investigated by Dunst, Hamby et al (2000), by collecting data from 3300 caregivers of children who are at risk of developmental delays. They attempted to investigate what are the main sources of naturally occurring learning

opportunities, and the results suggested 22 main sources or activities that are either home or community based. While these findings managed to direct the researchers to common activities that are essential for naturally occurring learning opportunities, they have also concluded the imperative effect of context and social or cultural backgrounds on these activities. This begs the question of how the contextual and cultural differences affect the impact of using natural environment or naturally occurring learning opportunities within EI programs. This question points to an essential aspect of the EI intervention and its relation to context and culture of the family.

The key elements of family centred service are clearly defined in the literature (Dunst, 1985, Dempsey and Dunst, 2004, Dunst et al., 2002). The general consensus includes the following (Dunst, 2002, Dempsey et al., 2009, Dempsey and Keen, 2008, Bamm and Rosenbaum, 2008):

- The family unit is the main authority regarding the child's health, and they know the child's needs and strengths best.
- The role of the family is best achieved by supporting and empowering them to make well informed decisions regarding their child's health.
- Services provided for the child are most effective if presented within the child's natural environment, and carried over by the family within their daily routines.
- Support to the family include; information, training, resources, as well as directing them to all other community resources.

- Planning and undertaking the intervention is achieved through collaboration between the family and the professional who work as partners in this process.

The implementation of these elements has been included within the policies governing early childhood services at several countries such as USA and Australia. However, when looking at the actual use of these principles we see a clear gap. Studies that have looked into the actual use of FCS within early intervention programmes from the perspectives of both professionals and families still debate whether the ideal FCS elements are being used (Hanna and Rodger, 2002). In a recent study (Bruder and Dunst, 2014) that looked into the views of families towards early intervention professionals, 50% of the participants reported they were not actively involved in their child's early intervention, a surprising result such as this one questions the reality of family centred care within early intervention.

As for the EI professionals; in a study by (Colyvas et al., 2010) where 40 videotapes of home based early intervention sessions were studied, the researchers found that occupational therapists who used a more traditional model used a more hands-on approach while the caregivers took a passive and observing role, and while therapists who used a participation-based model did involve the caregiver actively. This was not always done in an intentional manner, but rather incidental learning was dominant.

In another study (Thompson, 1998) where 10 mothers of children using early intervention services in Australia were interviewed, the findings reflected the

disconnection between what the mothers perceived as ideal EI programmes, and what they actually received. Almost all mothers in this study described a more "hands-on" intervention, where the occupational therapists focused on the child rather than on the whole family. What is interesting in this study is the evident contrast between the information provided for the mothers; which is clearly positive when most participants actually had a good understanding of the ideal EI services, and the actual application of these services which evidently did not utilize all the key elements of a family centred care EI.

Although there is an abundance of empirical evidence to support the importance of implementing key elements of family centred model FCM within early intervention, and while several countries have included these key elements as part of the policies governing early childhood programmes, there are also several studies that suggest a distinct gap between the "ideal FCM" and what is actually happening in the field (Hanna and Rodger, 2002). Some researchers have attributed this gap to two main factors; one is related to the professionals, as evidence indicate that professionals find using FCM, specifically moving away from the traditional "hands-on" approach, as difficult and challenging, two is the development of policies and the dominant cultures within organizations which still does not support FCM (Hanna and Rodger, 2002).

One possible factor that is affecting the implementation of a family centred EI programmes could be related to the prescriptive nature of these programmes. While social theories refer to the individuality of families as a set of circumstances

combining social, cultural, and economical factors, which build together a unique picture of each family (Edwards et al., 2003), EI programmes are set to provide a "fit-all" intervention, based on family centred care, but lacking the necessary modifications that ought to be installed to fit each family individually, following a thorough investigation of the needs and priorities of each family. This factor is addressed by (Feldman, 2008) where a call for more tailored EI programmes is initiated. This new perspective on EI programmes is referred to as a future necessity, where EI practitioners are encouraged to look at each family as a set of unique circumstances, which require adjustment to the intervention to meet those social needs (as in the different types of family units), the cultural needs (specific to the cultural background of both the family and the practitioner), and the economic needs (which would take into consideration the specific demands put on the family).

In other words; the current picture of EI programmes, where family centred care is used based on the empirically investigated key elements is in need of a measure of flexibility, where families initially cooperate with the EI practitioners to understand the needs and priorities of the family as a unit, the different types of support available formally or informally, and the specific circumstances that are affecting the daily life of this family. Then the family cooperate with the therapists to build a tailored EI programme, which may use the natural environment as the main setting for the intervention, if that is what this family needs, and it may require specific types of help-giving practices that cater to the social and cultural needs of the family.

For such flexibility to become a reality within family centred model, we need research looking into the various factors that affect family-professional cooperation; including 1) the individuality of family units be it the structure of the family including single parent's families, extended families, or any other variations, and the social impact of these structures, 2) the cultural uniqueness of the families, especially immigrant families living within culturally different countries; and 3) the socio-economic factors that may pose a significant effect on the process of the intervention.

1.4.2.2. Family-therapist collaboration within different models:

There are different models that govern the family-therapist collaboration within social work, Dunst et al (2002) describes a framework to explain how this collaboration changes from one model to another. They describe a continuum where on one side there are models that set the professionals as the centre or leader of this collaboration, where they hold the authority to make decisions concerning the child's care, and they inform the family of which interventions they deem necessary. Under these models the family is perceived as less informed in what their child needs, and the professionals are set as the experts guiding the intervention process.

Among these models the literature describes the medical model, the paternalistic model, and the expert-based help giving model. All of which share the same main characteristics of viewing the professional as the expert and the decision maker in the intervention.

On the other hand, there is the family allied model where the families are enlisted by the professionals to assist and implement the intervention, however; within this model the professional remains the leader and expert in this collaboration, while the family's role extends towards more participation in the intervention; but under the guidance and tutorage of the professional.

Families hold yet more active role in the family focused model; they are provided by the professionals with limited options regarding their child's care, from which the family are to choose and make decisions regarding how the intervention should go, this guided choice allows families a limited level of authority while maintaining the professional's expert leadership of the intervention by providing the families with the options that the professionals deem reasonable based on the resources, support, and services available.

Family-centred models are found at the other end of the continuum; where the family become the active partners of the professional, they hold the authority and power to make decisions, and are perceived as capable of making these decisions based on the best choices available for the child, at the same time; professional's role changes to become an agent for the family, where they assist the family and provide them with the necessary support and resources when needed.

This framework looks into three main distinguishable features of any model within early intervention programs; the role of the professional, the active vs. passive role of the family, and the main authority to make the decisions; these features play a distinct role in shaping the collaboration between family and professionals within

early intervention programmes.

The struggle that the therapists face when using FCM is usually focused on how to build and maintain a collaborative relationship with the family, this struggle might be due to the variations in family constructs and needs, while therapists are required to use respect and friendly attitude when interacting with the family, they need a variety of skills that fit with each unique family, which is in a way similar to the set of skills that the therapists utilize when dealing with different clients, but with further skills in handling the unique needs of a family as a unit.

1.5. Conclusion:

This introduction to the study focused on presenting the motivation behind the study, a description of occupational therapy and early intervention within Jordan, and a preliminary literature review.

In the following chapters we will look into the study looking into the collaboration between occupational therapists and parents of children using early intervention programmes in Jordan, the aim of this study is to explore how early intervention programmes use the family-centred model within Jordan, and specifically to:

1. Understand the perspectives of families regarding their role within the intervention, and what steps were taken by occupational therapists to establish/encourage this role.
2. Explore the perspectives of occupational therapists on how they facilitate family-therapist collaboration within early intervention programmes.

3. Generate a theory to describe parent-therapist collaboration within early intervention in Jordan.

The design of this thesis is intended to take you through the chronological progress of the study, leading to the concluding arguments and recommendations. The choice for this design complements the methodological approach used in this study which is Constructivist Grounded Theory, and is intended to give a true representation of how this study was conducted, but more importantly; it is chosen to help you as a reader to immerse yourself in the motivation behind the study, then the process of collecting data, analysis, and the interpretation of the resulting findings. The ultimate hope is to engage you with the process of the development of decisions, then the emergence of conclusions.

The thesis includes seven chapters, beginning with the first chapter where I have presented an introduction to the main topic of the study, and a discussion of the motivation behind it, followed by an introduction of the concepts of early intervention programmes and Family centred models to reflect the level of knowledge I had before starting the study, it was written prior to data collection and I have intentionally preserved it without adding any new sections in later stages, aiming to provide you with an actual view of the background theories and extant concepts which were used to design the study. The political and cultural context of the study is presented as a contextual background to frame the motivation behind this study, as well as providing an understanding of occupational therapy in Jordan.

The second chapter focuses on the methodological approach used to conduct the study, and the different methods used to collect data. Due to the complex nature of the topic being studied the second chapter details the different stages of the research complimented with a time frame to explain each stage. The chapter also discusses how the research was carried out in Jordan, focusing on the ethical issues and recruitment methods.

The third chapter details the analysis process and gives an overview of each analysis step supported with examples to illustrate again the methodological approach which was underlying the different stages of analysis. This is followed by presenting the findings from the first phase of the study, and the main themes that resulted. The second phase of the study is discussed in the fourth chapter, which presents in details the main findings and gives examples from data to describe the analysis process, concluding with an overview of the main themes.

The main findings from the research are presented as a theoretical framework within the fifth chapter, where the different links between the main themes are discussed, explaining how the results from the first and second phases have merged to produce a framework to explain parent-therapist collaboration within early intervention programmes, and how the political and cultural contexts which were discussed in the first chapter are influencing the results.

The discussion of the findings from this research are presented in the sixth chapter, where an in-depth look at the literature in the field of early intervention and family centred practice is discussed, linking to the resulting themes and framework to

place them within the current literature. The seventh and final chapter presents the conclusions of this research in the field of occupational therapy, specifically within the Jordanian culture, followed with the recommendations and limitations encountered in this research.

2. Chapter two: Methodology and Research design

2.1. Research methodology:

This chapter presents the methodological approach I have used in this study. The aim is to describe the choices I have made regarding the design and method, and provide a rationale behind these choices. The start of the chapter is dedicated to exploring different research methodologies available, then narrowing down to the chosen methodology with a more detailed discussion. The second section describes the study design by detailing the recruitment and data collection process, as well as the ethical considerations faced.

2.1.1. Introduction:

In this study I explore how early intervention programmes use the family-centred model within Jordan, by looking into the parent- therapist collaboration. I consider this collaboration as a specific type of human interaction, and attempt to understand the complex process of constructing it. I ask: what are the perspectives of both involved parties concerning their roles in this collaboration? What are the possible social or cultural contextual influences on it, as well as the effect of policies and regulations within the early intervention centre on this process?

When planning this research I have started with developing the questions that I hope to answer. My previous experience as an occupational therapist had a prominent role here. As an experienced occupational therapist who worked for several years within an early intervention programme in Jordan, I have used my

experiences as starting points for the research aims, and motivational drives to design a study that is relevant to the actual work within early intervention programmes.

By establishing the research question, I moved to consider which methodological approach to use, starting with whether to use quantitative or qualitative methodologies. To answer this question I have considered the aim of this research; what do I want to know? Am I interested in describing or understanding an existing phenomenon? And do I aim to produce findings that could be generalised to the whole population? These questions prompted me to think of the research methodology as a road I am using to reach a specific destination (the findings); do I want to include this road as part of my journey? Or am I interested more in the destination?

Considering these questions has led me to choose a methodology that will provide an understanding of the parent-therapist collaboration as a construct, at the same time acknowledge my role as a researcher in co-constructing this understanding with the research participants, thus attempt to focus on both the journey and the destination.

2.1.2. **Qualitative vs. quantitative methodologies:**

The research literature describes several differences between qualitative and quantitative research methodologies, ranging from data gathering methods, sample size, analysis methods, and the promise of generalising data (Green and Thorogood, 2013). However; the essential difference is in the epistemological root

of each type of research.

Quantitative research is based on positivism, a philosophical view of science and knowledge, where reality is assumed to exist 'out there' separately from the human understanding (Bowling, 2014). Three main elements describe positivism: (1) empiricism; which stipulates the study of observable phenomenon only, (2) unity of methods; which predicts that all different sciences will eventually mature and use the same methods of enquiry, (3) value-free inquiry; where science is described as objective, neutral, and separate from the influence of society (Berg et al., 2004).

Positivism uses deductive principles to measure a phenomenon, assuming that human behaviour is a reaction to external stimuli, and -like any object- could be observed and measured using scientific methods (Bowling, 2014). This deductive approach begins with an idea, from which a hypothesis or theory is formed, then applying scientific methods of data collection and analysis to test the hypothesis.

Qualitative research on the other hand uses an inductive approach for enquiry (Thomas and Magilvy, 2011), where reasoning begins with observations, which form ideas and general statements that evolve into testable hypotheses, and could be further tested by more observations.

The epistemological foundations of qualitative research are largely based on interpretivist and social constructivism. Both epistemologies oppose positivism on the view of reality, and distinguish between the study of objects and humans

(Green and Thorogood, 2013). The Interpretivist paradigm places the value of enquiry on understanding humans perspectives of reality. People are able to make sense of their place in the world, and unlike objects will behave and form their own views on how a researcher studies them. Thus interpretivist paradigm focuses on understanding how people perceive their world, and seek to describe phenomenon using expressions of language and communication.

Social constructivism criticises the notion that there is one pre-existing reality to explore, and assumes reality to be an outcome of human processes, affected by historical, social, and political context. And thus, when attempting to study any phenomena, constructivists aim to study the construction of these processes within their context (Thomas and Magilvy, 2011).

Each branch of scientific enquiry presents a distinct perspective to the scientific world (Berg et al., 2004). Quantitative research seeks explanation or causation, the goal is precise, objective and gathers measurable data, which can be analysed using statistical procedures. On the other hand, in qualitative research the ambience and nature of the phenomena is in question, aiming to study quality rather than quantity, the researcher looks for the why, when, and how. At the same time, the researcher presents her results using words, descriptions, and images (Thomas and Magilvy, 2011).

There are different methodologies used within qualitative research, based on what is accounted for as valid knowledge, or how to phrase the research question. Despite this qualitative research has general characteristics that are shared among

most approaches, including; a preference to study phenomena within their natural environment, a focus on understanding, reflexivity, and a flexibility in the research strategy (Green and Thorogood, 2013).

It is this evident focus on understanding the phenomena rather than measuring it that has an appeal for this specific research. Qualitative research allows the researcher to listen to the stories of people, without presuming a specific direction of these stories, encouraging the understanding of what each participant has to add, and permitting the researcher to use their own understanding as a part of the research process, while providing the researcher with reflexivity as a tool to maintain an awareness of their role within the research (Thomas and Magilvy, 2011).

Qualitative research considers the position of the participants as individuals with their own beliefs, specific behaviours, and perspectives, while including the context as part of the research process (Berg et al., 2004). This promotes a holistic understanding of the phenomena in question, rather than considering a specific question about the phenomena and isolating this question to be able to quantify the answer, which is more common in quantitative research. So considering the research methodology as a road that leads to the findings, in qualitative research this road is perceived as part of the journey and would have an effect on how the findings are understood.

2.1.3. **Epistemological paradigms in qualitative research:**

Qualitative research is based on different epistemological approaches such as the interpretative approach, social constructionism, or critical approaches (Green and Thorogood, 2013). Each of these methodologies seek to understand reality in a different way; whether it is through understanding how participants interpret reality, which is the foundation of the interpretative approach; considering the process with which reality is constructed based on historical, social, and political processes, which is a constructivist approach; or through locating the phenomenon within a social structure and analysing this structure, as adopted by critical approaches.

In considering the differences between qualitative and quantitative research I have decided on using a qualitative methodology. This decision stemmed from the focus of this research; which is to understand the process of developing a therapeutic collaboration between therapists and families of children within an early intervention programme. It was clear from the beginning that the aim of this research was directed more to answering what is the definition of this collaboration from the perspectives of the participants, how is this therapeutic collaboration formed, and why is it formed in this specific way and not in another? All of these questions are better answered using one of the approaches of qualitative research.

By considering the nature of these questions it was clear that there are essentially two different interests within the research aim; the curiosity to understand how

individuals (in this case the therapists and families) perceive a specific type of relationship (which is therapist-family collaboration), and at the same time form an understanding of how this one relationship is constructed/formed within a health programme (which is the early intervention).

The first interest revolves around considering how people interpret a phenomena; a focus that is related more to interpretivist. By aiming to understand how families and therapists define their roles within a therapeutic relationship, I am interested more in their interpretation of these roles rather than the reality of the roles, so it is the perspectives of the participants that are being studied. On the other hand; focusing on the process with which a therapeutic collaboration is formed within the early intervention programme leads to a constructivist approach, by considering the possible social and cultural influences that might affect how this relationship is formed, as well as the influence of the policies within the early intervention programme.

This led me to consider whether focusing on one of these two interests is sufficient to understanding therapist-family collaboration. While it is possible to maintain a specific focus on the perspectives of therapists and families as the aim of the research, it might provide an incomplete picture of this collaboration. At this point my own experience in working at an early intervention programme, and being involved as a therapist in many therapeutic collaborations with families has given me an inside look at the impact of both aims; the perspectives of families and therapists, and the process of constructing this collaboration within a social and

culturally specific context. Thus; my focus within this research is on using an interpretivist approach based on social constructivism.

2.1.4. **Why Constructivist Grounded theory:**

The pillar of qualitative research with an interpretivist approach is founded on the empathetic understanding of people's experiences, with the emphasis on the impact of contextual factors such as time and place which will have a direct effect on how people understand and express their own experiences. Thus; both researcher and participants are involved in the construction of this understanding, which means the researcher needs to develop awareness of their role in collecting and analysing data.

2.1.4.1. Other approaches considered:

While Grounded theory was the first qualitative approach considered for my study, as it encompasses the epistemological view point with which I have looked at the research topic, I did, however; consider using phenomenology as a methodological approach for this study, particularly using Interpretative phenomenological analysis (Chapman and Smith, 2002).

However; I was aware that the parent-therapist collaboration is a human relationship that is impacted by contextual factors, and thus I looked for a methodological approach that will give an emphasis to the context as much as the participants. This led me to give preference to grounded theory as it facilitates studying a phenomenon and the different contextual factors impacting it (Carpenter and Suto, 2008).

2.1.4.2. Grounded theory:

Grounded theory is a qualitative methodology that has been used within a wide range of disciplines including healthcare research (Mills et al., 2006, Green and Thorogood, 2013, Thornberg, 2012). The focus of this methodology is on constructing an understanding of human behaviour through a process of inductive data collection, followed by the use of constant comparison to analyse and compare data at different levels. The researcher continuously moves forward with data to form categories, then returns to initial data or employs theoretical sampling to gather more data, all with the aim of producing a theory that is grounded in the participants' experiences.

The emphasis of grounded theory on the process rather than the resulting behaviour resonated with the aim of this specific research. I have found the prospect of implementing different strategies to construct an understanding of how research participants perceive their roles within a therapeutic relationship interesting, as well as the promise of forming a theory that is grounded in the expressed experiences of the participants. At the same time the emphasis given to contextual factors such as social, cultural, or political aspects; which is fundamental in Constructivist grounded theory; provided a complete fit with the two main aims of my research project.

To be able to explain how grounded theory is used as a methodology to collect and analyse data in this research, it is important to visit the historical development of this methodology, and then describe the Constructivist school within grounded

theory. Several of the fundamental concepts within this methodology will be described in an effort to present a complete picture of how these concepts were utilised later.

2.1.4.3. Historical development of Grounded Theory:

When sociologists Barney G. Glaser and Anslem L. Strauss published their book The Discovery of Grounded Theory: Strategies for Qualitative Research in 1967, they managed to spark an interest in qualitative research among researchers and graduate students, despite the widespread view of qualitative research at the time as unsystematic, biased, and anecdotal (Charmaz, 2014). The proposition of Glaser and Strauss; of a systematic qualitative approach, alongside practical strategies and guidelines to generate theories that are grounded in data, contrasted with the dominant approach adopted by both quantitative and qualitative researchers to use existing theories for the purpose of deducting hypotheses. The effect of this book crystallised in the shift from using qualitative methods merely as a first step to produce quantitative instruments within research, to a standalone credible and rigorous methodological approach, equipped with valid strategies that can be used to create new theories in sociology and other fields of science.

Originally the traditional grounded theory adhered to notions derived from positivism; such as the necessity for the researcher to distance themselves from any influences and immerse themselves in data, or as constantly referred to in the literature as tabula rasa, or blank page (Mills et al., 2006). This emphasis is derived from the view that knowledge is there for researchers to find and explore, and by

immersing oneself in the data; as encouraged by Glaser (Glaser and Strauss, 2009); while ensuring no influence from preconceived notions, the researcher will be able to explore data and consequently produce theories that are “grounded” in data alone (Thornberg, 2012).

Grounded theory’s distinct merge of two rather contrasting disciplines in sociology- positivism and pragmatism- provided the research community with an enlightened approach to qualitative research (Charmaz, 2014). The systematic guidelines designed by Glaser to codify qualitative research, which reflected his quantitative training, adopted a positivist epistemological logic, of which he later described in detail in his book Theoretical Sensitivity (1978). Strauss’s more pragmatist background inspired the focus on more subjective, social, and human meanings; which was reflected in the grounded theory’s focus on process and the study of action rather than the structure.

The underlying assumption that the originators of Grounded theory adopted in 1967 of the importance of isolating the researcher from the external influence of preconceived ideas, is one that generated great controversy over the years. While Glaser adhered to this original assumption, Strauss moved towards a more lenient perspective where he acknowledged the value of reviewing previous works in a short and unsystematic manner. This new perspective was further expanded by constructivists such as Charmaz (2014) who criticised the unrealistic assumption of a state where the researcher could be a blank sheet and unaffected by previous knowledge and experience when approaching data.

The original description of grounded theory in 1967 has sparked an interest as well as a long standing argument between qualitative researchers. The two founders of grounded theory moved to develop two different schools in this methodology; the traditional GT lead by Glaser which adhered to many of the epistemological foundations described in the book The Discovery of Grounded Theory: Strategies for Qualitative Research (Glaser and Strauss, 2009). And the more pragmatic and slightly more flexible grounded theory that was described by Strauss and Corbin in several later books and publications (Strauss and Corbin, 1994, Strauss and Corbin, 1997, Strauss and Corbin, 1990). This school in GT described as evolved grounded theory (Mills et al., 2006) focused on describing strategies and techniques to help researchers apply the rather complex principles of GT (Clarke, 2007, Charmaz and Belgrave, 2002). In their famous book Basics of qualitative research (1990) Strauss and Corbin moved to a more liberal stance concerning the research process; declaring that "all kinds of literature can be used before a research study is begun [...]" (Strauss & Corbin 1990, p.56).

This evolved grounded theory differed from Glaser's traditional one on an epistemological level, although Strauss and Corbin did not address the underpinning paradigm of thought in relation to their method directly in any of their books. They did however visit this issue in a chapter they wrote in 1994 (Strauss and Corbin, 1994) where they described their take on GT by rejecting the positivist position of Glaser regarding GT, and declaring they do not believe in "pre-existing" reality but rather "our position is that truth is enacted" (p. 279).

The difference between these two schools in Grounded theory did however constitute one of the most interesting characteristics of grounded theory. As a methodology there is a promising flexibility in using grounded theory based on different epistemological paradigms, while preserving the practical nature of this methodology. Grounded theory has moved from a specific version of one qualitative methodology, to an umbrella that contains different schools of thought, and allows for further methodological development (Mills et al., 2006).

More researchers used grounded theory over the following years, and gradually some unveiled new possibilities for using this methodology beyond what Glaser and Strauss initially predicted (Mills et al., 2006). It was clear for many scholars, some of whom were students or colleagues of Strauss (Charmaz, 2000, Clarke, 2003, Lempert, 1997), that although the methodological procedures described by both the traditional and evolved GT schools did have an objectivist cast, grounded theory was inherently social constructivist. A new school in Grounded theory was gradually established, based on works of leading researchers such Charmaz (2014) and Clarke (2005). This new school moved beyond some of the restrictions and criticism of grounded theory, and established an increasingly expanding foundation within qualitative research.

2.1.4.4. Constructivist Grounded Theory:

Constructivist grounded theory is now considered as the third major school and a main methodological development in Grounded theory (Charmaz, 2014). Established on social constructivism and postmodernism, this methodology adopts

four main assumptions; (1) reality is constructed through a process of interaction influenced by context, (2) the interaction between the researcher and participants is the source of the research process, (3) both researcher and participants co-construct data and it is these data that are the product of the research, (4) the personalities of the researcher and participants have an influence on the research process and ultimately the data (Holstein and Gubrium, 2013, Charmaz, 2014).

The traditional GT adopts a positivist epistemology in seeking an explanation and the prediction of a theory at a general level, while preserving a distance between the gathered data and the context of the research or its process. The constructivist grounded theory on the other hand aims to produce an abstract understanding of a phenomena, by looking at this phenomena within a research process that is affected by specific circumstances. The focus on social constructivism as an epistemological foundation is best understood by considering how constructivists perceive an action. Charmaz (2014) considers any action as central within socially created situations and social structures. The researcher is involved in the research process by using their perspectives, position, and practices within the research situation. In essence, the researcher's involvement in the research process is in itself a circumstance of this "social" process, and thus; must have an effect on the findings, this also applies to the context of the research (Charmaz, 2014).

In her vision of a constructivist GT, Charmaz (2014) describes the research process as an interaction with different contextual levels; temporal, cultural, and structural. Charmaz (2014) encourages researchers to use their own recipe of available tools

to discover a reality that is emerging from this process. She acknowledges the specific perspective that constructivist GT have in looking at a research problem, but explains that this provides a foundation for the researchers to build a more generic statement based on temporal, cultural, and structural conditions.

Constructivist GT's view of the research process and the involvement of the researcher corresponds with this specific research project, and presents a well-established methodology that is suitable to address the research aims, especially as it supports my role as a researcher with a clinical background in the area of early intervention, and acknowledges the cultural and organisational context and their impact on the parent-therapist collaboration.

My decision to use constructivist grounded theory for this study revolved around three main promises of this methodology, in the following section I will discuss these three promises and describe their link to my study:

1) The interpretive understanding of subjects' meanings:

The central tenet of constructivist grounded theory according to Charmaz (2006) is it's potential to give voice to the participants in the study, a step necessary to illuminate the lived experiences of those participants. But this methodology's interpretive foundation facilitates the incorporation of multiple voices, with the inclusion of the contextual impact of political and cultural factors on the interpretation of participants' experiences.

This specific feature of constructivist grounded theory had an appeal to my study, with the potential of listening to different, even opposing, voices from parents and

therapists I was worried that one variant voice might be smothered by the majority, a possibility when the focus of the methodology is to look for similarities in perspectives, and represent what was common among the participants. At the same time the impact of policies and cultural context on the perspectives of the participants was anticipated to be evident, based on my previous experience as an EI therapist, however this effect could not be ignored and I expected a need to look at these contextual impacts to fully understand the lived experiences of the participants.

2) The Co-construction of Data:

A second promise of constructivist grounded theory is the understanding that reality is not discovered, but rather co-constructed by the researcher and the participants Charmaz (2006). This means that the understanding of how parents and therapists collaborate could not be discovered in one format, but rather within every interview a description of this collaboration is constructed, in a process that will reveal, potentially, the underlying influences from a variety of perspectives, while providing me as the researcher a central position to observe and even participate in this construction. I viewed this feature of constructivist grounded theory as very important, as I intended to look into the parent-therapist collaboration in depth and anticipated the complexity of this relationship.

3) The relativism of multiple social realities:

During my work as an EI therapist I have noticed the variety in perspectives and backgrounds of parents I have worked with, it was evident to me that even though my clients shared the common experience of having a child with disability, they

differed in their socioeconomic, cultural, and educational understanding of this experience. When it came to choosing the methodology for my study I was adamant to represent all the potentially different views I'm studying. Thus; with the relativism of multiple realities assumed by constructivist grounded theory I have found a suitable outlet for this variety, where the emphasis is given to capturing different participants' perspectives rather than one common concern.

2.1.5. **Criticisms and Limitations of qualitative research:**

Although qualitative research has expanded greatly within scientific research in social, healthcare, and other fields, there are still criticisms of this school of research. Mainly focused on what is claimed to be a lack of "scientific" approach, and a subjectivity that labels researchers who embark on a qualitative research (Golafshani, 2003).

One common criticism of qualitative research is the perceived lack of scientific methods to test the rigour and credibility of findings; or as termed the "subjectivity" of qualitative research (Green and Thorogood, 2013, Thomas and Magilvy, 2011). This criticism is based on a positivist view of research, where the importance of approaching any research topic with a clean slate is highlighted. This view however have been criticised as unrealistic by many researchers (Green and Thorogood, 2013, Bassett, 2006, Charmaz, 2014, Clarke, 2007); although an impartial approach to any research is encouraged by both qualitative and quantitative researchers, the influence of theories or assumptions on data analysis is unescapable. It is the awareness of such influence, and the ability to

acknowledge and deal with these assumptions openly that makes qualitative research credible (Charmaz, 2014).

Trustworthiness in qualitative research is achieved using a range of methods, be it the attention given to evidence through strategies of validating data such as triangulation, or approaching analytic accounts using a critical approach while maintaining a reflexive attitude to monitor the assumptions of the researcher (Green and Thorogood, 2013). In essence; although qualitative research utilizes different strategies to validate evidence and achieve neutrality than those used in quantitative research, this does not mean that qualitative research is in any way less “scientific” than quantitative.

2.1.5.1. Rigor, credibility, and transparency in qualitative research:

The value of qualitative research lies in its approach to human experiences, when researchers focus on the what, why, and how of any human action, they are providing a different set of data to the scientific world, one that is filling gaps in the evidence base, by answering questions in a manner that quantitative research lacks (Green and Thorogood, 2013). Experimental methods can describe an action with numbers and statistics, but it cannot explain what the action means to the individual, nor does it delve into the perceptions of people when they interact with each other, aspects of research that are essential for many fields of science, especially in health-related research.

Understanding one phenomena in an in-depth perspective is the aim of qualitative research, as the researcher focuses on collecting a variety of data to form a holistic

understanding of the topic of their study, they are in fact not concerned with generalising their findings to other areas, but are interested in exploring one phenomena or experience so they - or others - can build on this knowledge further (Thomas and Magilvy, 2011).

Qualitative Rigor refers to establishing trust or confidence in the findings of a research, through consistency and details in the research method, as well as collecting as much data on the phenomenon to enrich understanding it. It is important for the researcher in qualitative research to establish credibility and transparency in the method they are using to collect and analyse data. Credibility is achieved through representing a true description of the experiences of humans involved in the research, using member checking, reflexivity, and triangulation the researcher ensures they are relaying the actual perspectives of the participants. Triangulation could be achieved by using different sources of data to describe the same phenomena, thus verify findings (Hastings and Salkind, 2010). This specific form of triangulation is termed between-method triangulation. In this study I used multiple sources of data including observations, review records, and interviews with two groups (OT and parents) to ensure the credibility of the data and findings. Transparency refers to the clarity and explicit presentation of methods and procedures within the research, as well as the assumptions behind the design and the application of the method of data collection and analysis (Green and Thorogood, 2013). In qualitative research it is essential for the researcher to present the procedures they have used so as it could be replicated if needed, however; this does not necessarily mean that the findings could be replicated too

as there is a distinction between transparency for procedures or findings (Whittemore et al., 2014).

The researcher uses reflexivity to achieve a critical self-exploration of their assumptions, decisions, and self-interests at every stage in the research, ensuring they acknowledge their role and are aware of the potential influence of human nature on the procedures of data collection, analysis, and interpretation (Starks and Brown Trinidad, 2007).

2.2. Design and Method:

This study employed data collection from multiple resources over two phases; the first phase focused on the context of the EI programme, and included collecting data through the observation of occupational therapy sessions within the EI programme, parent-EI team meetings, and EI assessment, then a review of the EI programme records and therapy field notes. The second phase focused on semi-structured interviews with a sample of parents within the EI programme, and a sample of occupational therapists who worked or are still working in EI.

2.2.1. Theoretical sampling:

The sampling process for this study began in the first phase of data collection, which included observations of sessions and review of EI records. Theoretical sampling focuses on identifying the characteristics of potential participants while collecting data, by letting the data determine the direction of confirmation or contrasting through new sources of data (Charmaz, 2014, Thornberg, 2012). In the

beginning I have identified one EI programme in Jordan where the observations and field note review would happen. A list of the different centres in Jordan issued by the Higher Council for the Affairs of Persons with Disabilities HCD in Jordan (http://hcd.gov.jo) was used to establish which centres include EI programmes. This list included all the centres that provided rehabilitation for persons with disabilities in all the cities of Jordan with a total of 288 centres. I narrowed down the list to centres in the city of Amman to limit traveling within one city, then centres that provided occupational therapy which were 50 centres. The next step was to select centres that also provided EI programmes; this resulted in 28 centres In Amman area. The selection criteria for the EI centre included the following:

1. The centre in the city of Amman
2. Services should include occupational therapy
3. Services are documented in records and field notes
4. EI process should include parent-therapist meetings
5. The programme is described as a Family-centred service

The criteria narrowed down the list to three EI centres: one was a privately owned centre, when I contacted them they expressed worries related to the reaction of their costumers towards opening records for research purpose, and they refused to allow access to their records or observing sessions based on this worry. The second centre did not reply to the request at all, I have learned at a later time that the centre was closed during the summer time which coincided with my data collection. The third centre approved for the research to be conducted at the EI programme, the time frame for the data collection was acceptable to them and

thus I started the arrangements to begin the first phase. To make sure that the EI centre had a clear understanding of what the research aimed to achieve, a copy of the research proposal was sent to the manager of the centre, this proposal described the aims of the research, the methods that will be used for data gathering, and a brief literature review.

For the first phase of data collection I observed sessions randomly, depending on the daily schedule of the EI programme. After analysing the data I determined the characteristics of the participants in the second phase of data collection, using theoretical sampling to establish which participants will potentially clarify the process of the EI at its different stages, thus decided to interview parents at the start of the programme and also closer to finishing the EI programme. I have also identified the need to interview occupational therapists with a variety in their experience, as I observed differences in therapists' skills in interacting with the parents, a difference I hypothesised to be linked to the length of their experience working in EI.

2.2.1.1. Sampling for phase one:

2.2.1.1.1. Early Intervention records:

The review of EI records and field notes aimed to establish the intervention process followed within this programme, as well as the policies enforced by the programme as a design for the intervention. This contextual understanding of the policies and procedures would help me later in establishing the different stages of the intervention within which parent-therapist collaboration develops, in Constructivist grounded theory the studied phenomena is explored by considering the contextual

factors as well as the phenomena itself, highlighting the potential impact political and social context might have on the process (Thornberg, 2012, Charmaz, 2014).

The sampling of the records was based on the following criteria:

1. Active records to facilitate recruiting the parents or therapists who still work with this child in the second phase of data collection.
2. The child receives occupational therapy sessions.

2.2.1.1.2. Observations of sessions and parent-team meetings:

For the second source of data collected in this phase which is observations, I relied on the daily schedule of the session, at the start of each day I consulted the EI manager who gave me a list of the OT sessions, parent-team meetings, or assessments scheduled for the day. In many cases the sessions or meetings would be cancelled because the parents did not show up or were late. Thus; the sessions were observed randomly, and the only criteria I observed is that an occupational therapist is there in the session.

2.2.1.2. Sampling for the phase two:

The second phase of the study focused on semi-structured interviews with a sample of parents who use EI services, and a sample of occupational therapists who previously or currently worked at an EI programme. I decided on the inclusion criteria for each group following the data analysis of the first phase, and depending on the data I needed to confirm or contrast.

The inclusion criteria for the parents' group were:

1. Family with a child no older than 6 years.
2. The child received occupational therapy as part of the early intervention programme.

The inclusion criteria for the occupational therapist group:

1. Members of the Jordanian Society for Occupational Therapy JSOT.
2. Jordanian occupational therapists who received their degree in OT at a Jordanian University.
3. Participants who have at least 6 months of experience working at an EI programme in Jordan.

Recruitment of Parents:

The aim of the recruitment was to conduct interviews with a random sample of the parents who still receive EI services. Considering that the parent-therapist collaboration is studied as a construct which is developed over time based on the principles of constructivist grounded theory (Charmaz, 2014), I needed to collect data from parents who are experiencing this collaboration at different stages. Thus, I decided to try and interview parents who are at different stages of the intervention, this meant interviewing parents who started the intervention at least 6 months before, parents who had been in this programme for a couple of years, and parents who were concluding the programme soon. To achieve this variety, I organized with the EI manager at the start of the second phase of data collection to check the daily schedule of the team. She gave me a list of the parents and at which stage they are in the intervention, and I highlighted the possible days for data

collection. The choice for parents was not intentional; it depended on who was available at the days I had scheduled for data collection.

My priority was to make as little inconvenience for the parents as possible, so while they were waiting for the session to start I asked them if it is possible to sit for an interview later. Those who were not busy and willing to participate were given the participants information sheet and consent form to read (Appendix 1 Participant consent form and Appendix 2 Participant Information Sheet), and were invited to wait in the waiting room after the session was concluded. Some parents were busy with other commitments after the EI session so they refused to participate, others were not interested in participating. This process of recruitment continued over six days, fourteen parents were approached to participate, and seven parents were available and willing to take part in the study.

This recruitment method ensured that the parents would have enough time to read and sign the consent form before the interview, it also ensured they were not coerced in any way to participate; if they were interested they would show up for the interview, if they did not want to participate they could simply leave after the EI session. The following Figure 1: Participant Recruitment Flow Chart for the parents' group describes the recruitment process for the parents:

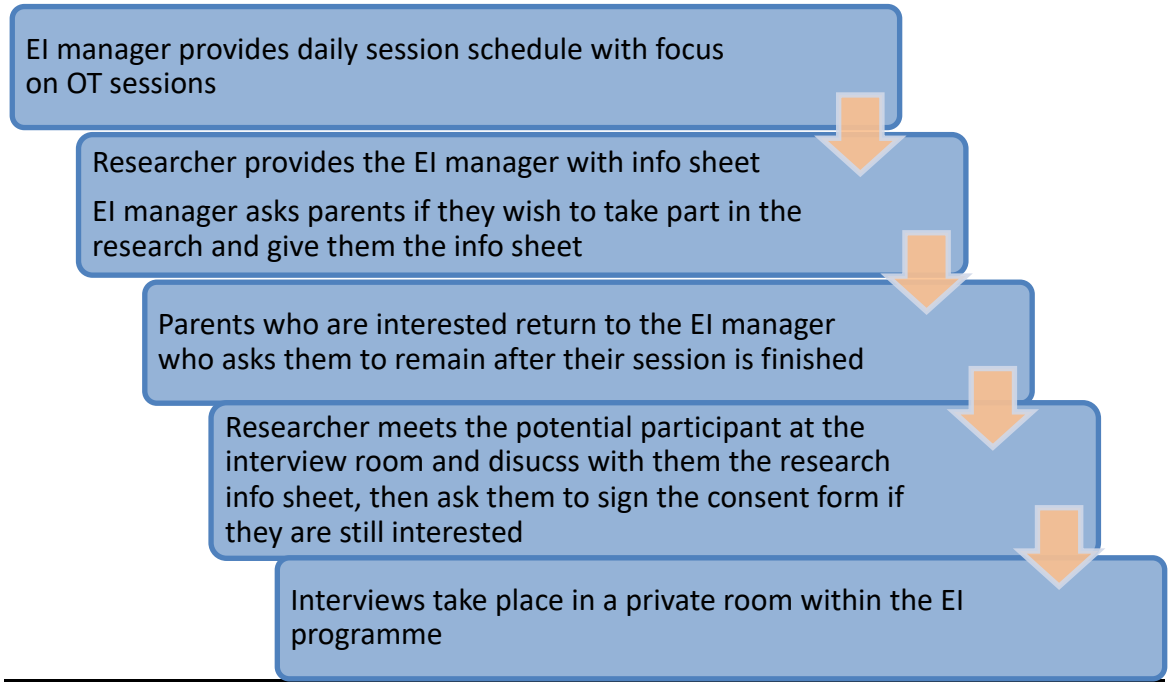


Figure 1: Participant Recruitment Flow Chart for the parents' group

Recruitment of Occupational therapists

In July 2017, the recruitment process began with posting an advertisement at the JOTS Facebook page. The advertisement invited therapists with at least 6 months experience in working at an EI programme to participate in the research. The advertisement was received well by the OT community on Facebook. Many therapists shared the post inviting their friends who might fit the criteria to participate. This moved to the speech therapy and physical therapy communities who also shared the post to invite more therapists.

Initially nine therapists responded to this advertisement, after contacting them to enquire further about their experience, I found out that five did not fit the criteria; two gained their experience in EI working outside Jordan at Gulf countries, and

three did not actually work within an EI programme but at a centre that serves children from all age groups.

Out of the four therapists who did fit the criteria, two offered to contact their friends who might be interested in this research. This resulted in adding three more therapists to the sample. After contacting those new participants I found out that one had travelled to Qatar, he did fit the criteria but was currently working in another country, he was interested in participating and agreed to a skype interview.

Two therapists were again suggested by one of the participants but after contacting them they explained that they had no experience in EI programmes but did work with the age group younger than 3 years. The total of therapists who were contacted in this research is 14 therapists; only 7 of those did actually work in an EI programme but one was working outside the country at the time of data collection. The other 7 therapists who were contacted had worked within paediatric settings that served younger children but did not actually have an EI programme. Those therapists did however initially claim they have EI experience, but when asked for details on their experience they admitted that it wasn't actually a formal programme, but they rather had young clients (aged below 3 years).
The following Figure 2: Recruitment process and number of OT who responded explains the number of therapists contacted, how they were recruited, and the number of therapists who met the inclusion criteria. The final number of the OT sample was 7 therapists, however one of them was working in another country and

thus could not participate in a focus group or is interviewed face to face, and the remaining 6 participating therapists were invited to participate in the focus group.

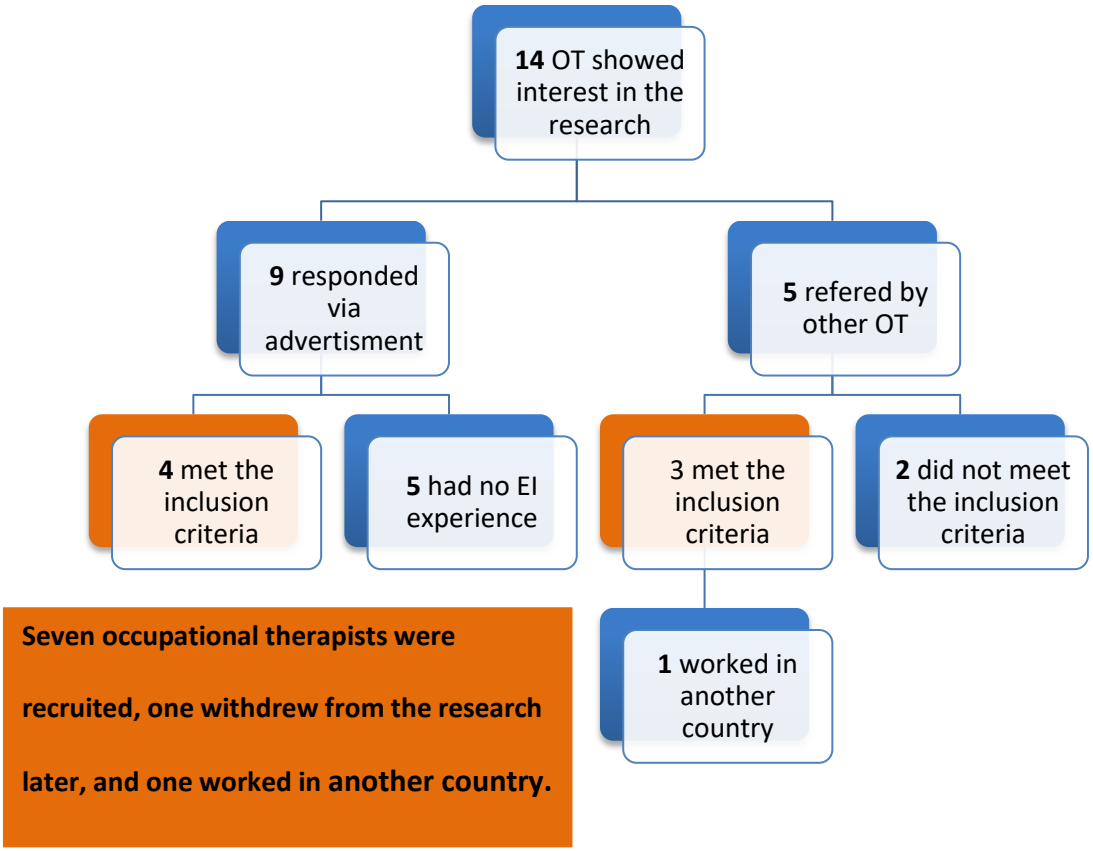


Figure 2: Recruitment process and number of OT who responded

Data collection was set to be carried out in Jordan at an early intervention EI centre. The nature of the research entailed that data be collected using five different resources including: review of the results of a previous study, observation of different instances of family-therapist interactions, review of the EI centre records, semi-structured interviews with the families of children using EI services, and a focus group for occupational therapists who specialised in EI. The methods of data collection in grounded theory allow the researcher to use a multitude of resources, in part to provide a variety of data which would enrich the research and describe the phenomenon from different perspectives (Urquhart, 2012).

Observations, record review, and semi-structured interviews are examples of data collection methods recommended by Charmaz for a constructivist grounded theory study (Charmaz, 2014).

The data collection process was planned over two phases: the first in December 2016 where I observed several sessions of OT within the EI programme, and reviewed the records of the programme. The second phase included the semi-structured interviews and the focus group (later replaced with semi-structured interviews), and was set in July 2017. I used the six months prior to the second phase to analyse available data and perform constant comparison, as well as using preliminary results to prepare an interview and focus group guide.

The following Figure 3: Data collection describes the data collection process:

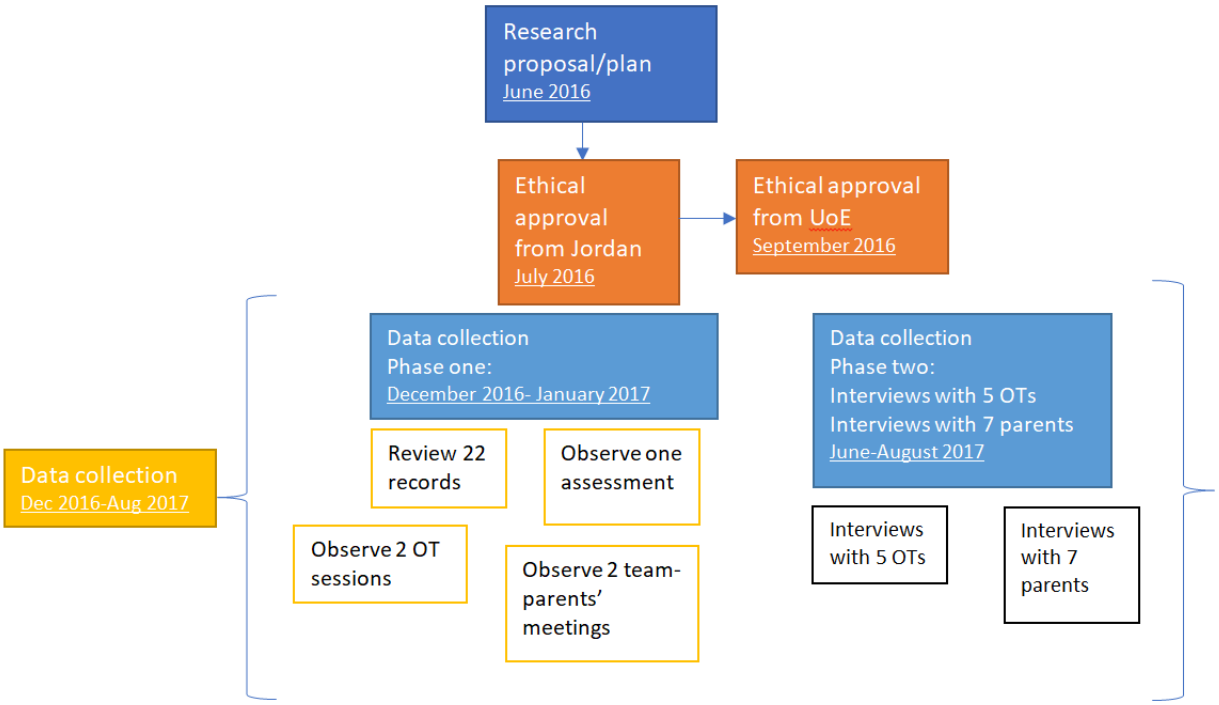


Figure 3: Data collection

2.2.1.3. Data collection Phase one:

Preparations for data collection:

The first step in preparing for the data gathering was to prepare the research documents, which included the research proposal, the participants' information sheet, and the consent form. These documents were initially prepared in English, but at a later stage were translated into Arabic. The Arabic version was used in the ethical approval application to the Jordanian Ethical committee, and the English version was used for the ethical approval application process at the University of Essex.

Prior to any data gathering activities there were several steps taken to organize and prepare for my visit. The short time period available for each data gathering phase

required that all practical issues be organized ahead of time. Five months before conducting the first phase of data gathering I visited Jordan to apply for the ethical approval committee within the Jordanian Ministry of Health.

To prepare for collecting observations during the first phase of data gathering, I prepared a general framework to organize my observations, and to ensure a systematic method of data collection (Appendix 3 Observations framework). This framework was prepared based on a review of the intended aims of the observations, as well as the best method to ensure quick and simple documentation of the observations.

The framework focused on three main areas to observe:

- The environment; which included the setting of the session, the tools and materials used, and the location of each person within the room.
- The role of the therapist; including observations of what the role they assumed evident in the words they used, facial expressions, body language, and manner of interacting with the other person.
- The role of the parent; including their responses, the comments they gave, their part within the session, and their interaction with the therapist and child.

The first data gathering visit:

The first phase of data gathering took place between the 13th December 2016 and the 17th January 2017. I travelled to the city of Amman in Jordan to collect data

from the EI centre which included a review of the programme records, and observations of family-therapists interaction within different types of sessions. The plan for this visit was to observe team-therapist meetings, and OT sessions, however; the EI manager had mentioned that the first week of January may also include evaluation sessions for new children at the EI programme. This seemed like a good opportunity to observe the first contact between the team and the child and family.

On the first day at the EI centre I was introduced to the EI team and took a tour of the setting. It was important to introduce the research to the staff involved so as to gain their cooperation, and answer any possible questions they have. The staff included two occupational therapists, who worked on alternate days at the EI programme and the school setting within the centre, their schedules were set so that only one therapist will be working at the EI programme in any given day of the week. The staff also included one trainee occupational therapist who observes some sessions as part of her overall training at the centre.

The tour around the setting of the EI programme allowed me to collect observations on the facilities and tools used, as well as to examine some of the information resources provided for the families on notice boards. The EI programme setting includes five therapy rooms (two individual and three group therapy rooms), a staff office, a waiting area, and an adjacent open play area. The first day also included a meeting with the EI manager. During this meeting I introduced the consent form and participants' information sheet. These forms

needed to fit with the centre's own consent forms. No modifications were made by the manager. I also discussed the schedule for data gathering; it was important to review the schedules of the therapists to make sure that I would be able to observe enough sessions, as well as have enough time to review the records.

The procedures of collecting data followed a specific course; after identifying which sessions to observe using the schedules of the therapists, the families were contacted via telephone to request their preliminary consent. On the day of the session I would approach the family before the start of the session to explain in detail the focus of the study, and what I will be doing within the session. If the family allow data collection they would be asked to sign the consent form. During the sessions my role was to present as little distraction as possible, written notes regarding the observed session were used instead of video recordings due to the centre's privacy policies which prohibit unnecessary recordings of interactions with the children. This did not present a difficulty for the data collection because the aim of the observation is to collect general notes regarding the family-therapist interaction, so recordings were not necessary.

During the full duration of this data gathering phase the following sessions were observed:

- Three family-team meetings
- Two individual sessions by occupational therapists
- One evaluation session by the EI team

An additional family-team meeting was observed; however, this meeting did not include an Occupational therapist. It became evident to me after the start of the meeting that the intervention for this child included occupational therapy at the beginning only, but after one month the child progressed very well and was discharged from the OT service. Since the family-team meetings are conducted every 6 months to discuss the progress of the child, the team decided to focus on the services that the child currently uses, and exclude OT from the meeting. The observations collected from this meeting were not used in the data analysis because the aim of the study is focused on occupational therapy in particular.

As for collecting data from records, I had initially examined the system used to organize the EI programme records, which divided the files of the children according to their birth year. To be able to build a complete picture of the records I decided to study samples from each age group. 22 records were examined during the duration of the data gathering. The method used to collect data included written notes of the records according to the following steps:

1. Study the files to establish the general template of the records; this step focused on understanding what the intervention process as reflected by the records is.
2. A detailed study of each intervention step using the documentation system; this included examining the same form template within each file to collect notes on how the team document their work.
3. Focused study of the forms related to family-team interactions; including

evaluation records, home visit records, and family-team meetings records.

4. Collect notes and examples of documented comments from families regarding their priorities and other problems they face.
5. Collect notes on documented comments about the families written by the team; especially comments within session notes and home visits.

By the end of the first phase of data collection I was able to achieve the aim of this visit, and the data provided sufficient information to begin data analysis. Throughout this phase I maintained a routine reflective diary which included recording audio at the end of each day to reflect on the procedures, and taking reflective written notes after the observation of every session.

2.2.1.4. Data collection Phase two:

Interviews with occupational therapists:

The plan for the second phase included conducting a focus group with the occupational therapists to promote a discussion between participants, utilising this discussion to collect different perspectives regarding early intervention in Jordan. During data collection I made plans with the recruited participants and scheduled the focus group according to their availability. The day before the focus group I contacted the participants to confirm their attendance, and one participant could not attend due to changes in her work schedule. However, the remaining five participants confirmed their attendance. On the day of the focus group one participant had a family emergency which prevented her participation and contacted me early morning to apologise. At the set time of the focus group I had

expected four participants to attend, but only two showed up, the other two did not answer their phones and so it was clear that they were not coming. This situation meant that I could not conduct the focus group because the number of participants did not allow a discussion, so I decided to do interviews with the two participants. However I had no interview guide prepared, what I had was some prompting questions that I intended to use within the focus group. To save the time of the participants I decided to us the prompting questions and try to conduct the interviews in a non-structured manner. The result was two interviews that were based on open questions where the participants led the discussion based on the main topic of the research.

Following this change of method I contacted the participants who could not show up to the focus group, to arrange a time for interviews at their convenience. I was able to interview three other participants at their work location, their managers at work were contacted before the interviews and they approval was gained. The participants were interviewed during their break time, the following diagram gives details of the data collection process and the final number of therapists who were interviewed Figure 4: Occupational therapists data collection procedures.

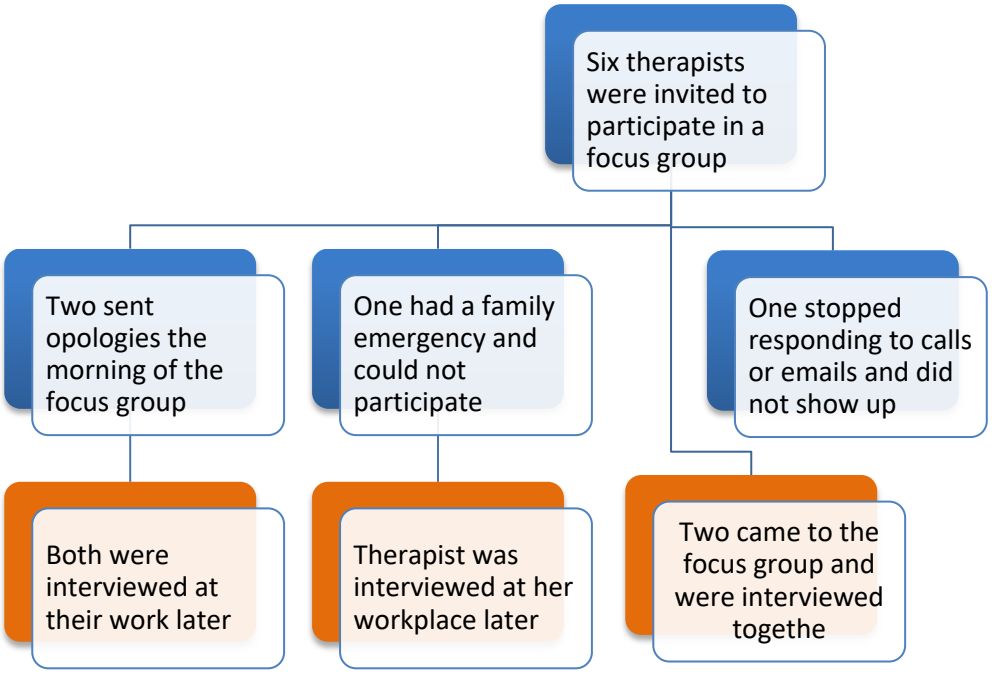


Figure 4: Occupational therapists data collection procedures

In each interview I followed the same procedures, once the participant was settled in the interview room I would present the research briefly using the information sheet, then discuss the consent form. The interviewee would then ask questions to clarify any points regarding the research, then they would sign the consent form. To start the interview I would set up the recording device on the table and use the interview guide (Appendix 4 Interview guide Occupational Therapist) to open a discussion about early intervention in Jordan. It was important to let the participant talk about their own experience and perspectives, so I did not necessarily follow the sequence of the questions, but took the lead from the participant regarding which topic they wanted to talk about first.

Whenever the participant mentioned something of interest I would ask them to elaborate or clarify their point of view, and if the participant concluded their talk

about one topic I would move on to another area based on the interview guide. At the conclusion of each interview I asked the participants for anything they wanted to add which was not discussed, this would be followed by an expression of gratitude for the participants' time and efforts. Once the participant left the room I used the recorder and my notebook to record my reflection on the interview, this included how I thought the interview went, any observations I had regarding the manner of the participant, and my initial thoughts regarding the discussion.

Interviews with parents:

The recruitment of the parents was conducted through the EI programme leader, I contacted her to obtain the daily schedule for the EI team and organised the days which I could conduct the interviews. My first concern was to make sure that I had the chance to interview parents who were at different stages in the EI programme, I had intended to look at EI process from the perspectives of the parents, and so I decided to interview parent who were just starting the programme, parents who are halfway through the programme, and parents who have concluded or were scheduled to conclude the programme soon.

The EI team leader advised me on the days when new parents were scheduled for sessions, and when it was more likely for parents who are finishing the programme to come to the centre. I arranged a schedule for my visits to the EI programme, and requested that the team leader allow me to talk to the parents as they were finishing their sessions.

The recruitment procedures were simple, whenever a parent finished their

scheduled session I asked them if they were interested in participating in a research. Those who showed interest were directed to the reception room where I talked to them and gave them the research information sheet and consent forms. The parents who decided to participate in the research after reading the information sheet were asked to sign the consent, and they were immediately interviewed. The interviews were conducted at the reception area which included a child-friendly play area so their children would be occupied close by, and a small room that ensured privacy which we used for the interview. Seven parents were interviewed throughout the month of August 2017, the following Table 1: Participating parents' information includes the Pseudonyms used for participating parents with the child's age and duration they have used EI services:

Participant	Gender	Child age	Duration within EI Programme
Majd	Male	5 years	2 years 6 months
Ihsan	Male	5 years	1 year
Lana	Female	2 years	8 months
Maya	Female	1 year 7 months	7 months
Noor	Female	5 years 6 months	2 years 3 months
Faten	Female	5 years 11 months	4 months
Yara	Female	5 years 6 months	1 year

Table 1: Participating parents' information

The first two interviews were with parents whose children were about to conclude

their EI programme, they both were visiting the centre to discuss school options for their children, their visit included meetings with the EI manager and some staff members. The EI manager asked them if they were interested in the research as their experience might be of help to review the EI programme. Both parents agreed and were interviewed.

During these two interviews I attempted to use an interview guide which was prepared to include general questions (Appendix 5 interview guide Parents). This interview guide was prepared based on the findings from phase one and the procedures of the interviews with therapists, although I had anticipated the need to use this guide merely as a suggestion because parents might have other topics to discuss, so these two interviews were also used to evaluate and change the interview guide. Following each interview I also recorded a reflection on how the parent reacted and my own impressions, I also listened to the two interviews to look for areas that need to be further discussed in the coming interviews, one of these topics was related to emotional support because both parents considered this as the main aim of the EI programme, this was a topic that I did not consider initially, and so I added a question to focus on the types of support the parents receive from the EI staff.

A second adjustment to the interview guide was added after the third interview, when the participant made a comparison between EI staff based on their personal traits and their communication style with her. This seemed to be linked to the role the parent took in the EI programme. And so for the remainder of the interviews I

added a question regarding what makes a staff member more helpful than the others. The next four interviews went smoothly and there were no adjustments to the interview guide. The following Figure 5: Iterative process within interviews with parents represents the process or changing the interview guide which had the iterative process particular to constructivist grounded theory methodology.

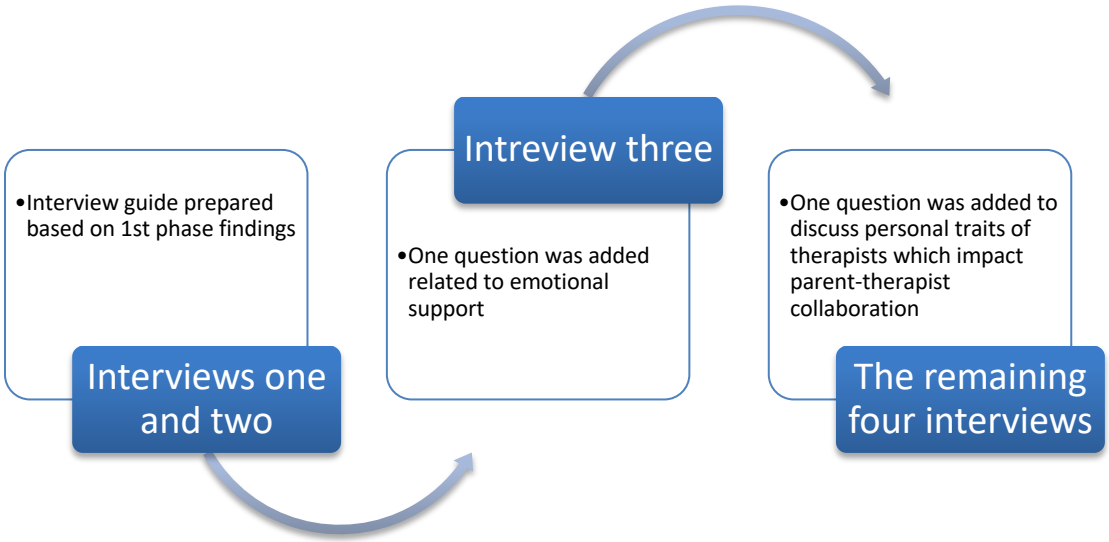


Figure 5: Iterative process within interviews with parents

2.2.2. Ethical consideration:

The design of this research included different consideration of potential ethical issues, mainly stemming from the researcher role and the possible impacts on the participants. In this section I will discuss these considerations and the steps taken within data collection and analysis to avoid any harm or disclosure of confidential data.

In the observations with the first phase I considered the possibility of witnessing a situation where the therapists might be using a technique that could harm the

child, it was important for me to think in advance of the way I will react to this situation if it happened, would it be better to stop the session; and consequently the data collection; to ensure no harm is done for the child? Or would it be better to report this after the session was concluded? Since I could not predict the nature of this harm I decided to keep the decision dependant on the situation, so if there was a n urgent need to stop the sessions I would do so, and if the technique might be harmful but with no immediate danger then I would discuss this with the therapists and EI manager after the conclusion of the session.

During the second phase I considered my position as a therapist who worked with or supervised the training of participating occupational therapists, because occupational therapy in Jordan is still a new profession, the community of therapists is small, and those who have clinical experience were mostly involved in the training of OT students. I anticipated interviewing therapists with whom I have worked in the past, or have trained at one stage of their education; I considered how to ensure those participants would open up in the interview without referring to my previous role, or worrying about contradicting my opinions. The cultural perspective prevailing in Jordan of respecting the teacher and adhering to their expert knowledge might interfere with the participants' expression of their opinions.

To overcome this possible challenge, I dedicated time while discussing the information sheet with the therapists before they sign the consent form to explain my role, I clarified that this research is aiming to understand the perspectives of the therapists, and that their opinions are not viewed as right or wrong, but rather

their perspectives are representing the reality of their work. I have also explained the steps I have taken to ensure the confidentiality of their views, including using pseudonyms and excluding any details that might be identifiable.

During the interviews with the parents, I faced a different challenge as three parents wanted to consult me as a therapist regarding their children's situation, this happened because I was introduced to the parents as an occupational therapist who doing her PhD, and this meant I held an expert position in front of the parents as the Jordanian culture gives persons with higher degrees an elevated status in terms of knowledge.

I have considered this issue before starting the data collection, and decided to inform the parent if they ask for technical advice to allow me to finish the interview, then dedicate some time afterword to answer their questions. I was however; aware that I need to be careful not to give technical advice unless I can establish there is potential harm if I don't, and prepared myself to invite the parents to discuss these issues with the EI team, or use one of the services in the community which pertains to their issue.

2.2.2.1. Regulatory ethical approvals:

Ethical approval was obtained from two different committees, the ethical committee in the Jordanian Ministry of Health (Appendix 6 Ethics approval from the Ministry of Health in Jordan), and the ethical committee in the University of Essex (Appendix 7 University of Essex ethics approval).

According to the regulations for health related research in Jordan, any research that involves patients or their families is required to apply for ethical approval from

the Ministry of Health, the application process involves preparing the research proposal, information sheet, and consent form, all in Arabic, as well as filling out an application form. After submitting these documents the committee chair interviews the researcher to clarify any related points. The final step is for the committee to study the application and make a decision. In July 2016 the application was approved and ethical approval was obtained.

The ethical approval process at the University of Essex was based on the approval from the first committee, as well as submitting the same documents (in English). Ethical approval was obtained in August 2016.

2.2.2.2. Confidentiality:

The anonymity of the participants was ensured by using a code for each participant from the outset of the study. This code replaced the name of the participant in all the records and data used, and was later used in the data analysis. Access to the data and consent forms which included the full names of the participants was password protected and limited to me.

All recordings are saved in one computer to maintain privacy and protection, while using a backup copy to ensure no loss of any data. The hard copies of all the research documents are kept in a locked cabinet at my work station.

The confidentiality of the therapists presented a more complex challenge, due to the small number of the OTs in Jordan, especially those working in EI. The identities of those participating in the research might be identified from their descriptions of

their work, thus; all references to place of work or type of setting were concealed when presenting the data. The therapists were ensured their anonymity by changing their names to codes in the records, and all information that might identify them such as number of years of experience, the university they graduated from, were also concealed from the data.

2.2.2.3. Informed consent:

Consent was obtained from all participants in the interviews, as well as during the observations. The process of obtaining consent followed the same system, the participants were offered the information sheet and given time to study the document, if they required any clarification or questions I answered them, then if they wished to participate they were asked to sign the consent form (Appendix 1 Participant consent form).

For the families participating the information sheet was given to them while they were in the waiting room of the centre, and they were asked to go to the office used for the research if they wish to participate. This gave the family an opportunity to read the information sheet without the presence of me or any staff members, and if they wished to leave without participating they had the opportunity without anyone asking them. This minimised coercion and ensured they had the freedom to leave without any staff member observing them.

The occupational therapists were sent the information sheet via email if they showed interest in the research. This gave them enough time to study the document and ask any questions over the email. Those who were interested were

invited for the interview, before starting the consent form was signed.

2.2.3. **Conclusion:**

In this chapter the methodology used for this research was discussed, as well as a description of the procedures for phase one and two in data collection. The methodological approached used in this research was also used to write this thesis, thus; the procedures of the data collection described in this chapter were interspersed with data analysis, starting with the analysis of data collected from phase one which took place before the start of data collection phase two, the findings from phase one were used to prepare interview guides for semi-structured interviews with the therapists and parents. Additionally; while conducting the interviews some cursory data analysis was conducted to establish if there is need to make adjustments to the interview guide. In the following chapter the analysis process will be detailed which followed the work of Charmaz (2014), and the findings from phase one will be presented to reflect the procedures of this analysis.

3. Chapter three: Phase one Analysis and Findings:

A constructivist Grounded Theory (CGT) analysis was adopted in this research, which consisted of several stages, starting with the initial coding stage which included line by line coding using comparative methods, followed by focused coding and theoretical coding. All through the analysis process, constant comparison and analysis note writing were used, as well as documenting reflective memos.

Charmaz (2014) describes the CGT analysis process as an attempt to understand the viewpoint of the participants, their stories, sentiments, and acts. Thus, the researcher has the opportunity to listen to the narrations of the participants and place them within a context comprised of social, cultural, and political layers, a process that will provide the researcher with a unique perspective into the phenomena or population studied. The analysis process is a journey where participants take the researcher through their own experiences, but what distinguishes the CGT analysis is the spiral route this journey takes. Raw data are returned to repeatedly during the advanced stages of the analysis, to maintain a grounded focus on the participants' experience, a technique celebrated within grounded theory literature as constant comparison.

3.1. Analysis process outline:

The procedures for the data analysis were as follows:

1- Open coding:

- Line by line coding for each set of data (observations, notes from records, or transcripts of interviews)
- Note taking and reflective memos

2- Focused coding:

- Compare codes between similar sets of data
- Sequential comparisons between different sets of data
- Highlight similarities and prominent views
- Theoretical coding

The analysis process for this research followed a similar path as described by Charmaz (2014), starting with the transcription of the various formats of data collected; field notes, observations, and interviews. As the raw data were all in Arabic, the first step in transcription was to translate word by word into English, a meticulous process were every word was examined to use the most suitable translation without losing the meaning intended.

An example for this process is when one of the therapists used the word (Nesayer -نسایر) to describe how she approaches her client's family, this word is from the Jordanian spoken dialect and its formal Arabic equivalent is (استرضاء - aistirda') which translates to appease, placate, or pacify. However, the therapist used this word to indicate a more negative manner, one where some sort of manipulation is used. While the Arabic word used by the therapist within the context of the discussion clearly indicated a slightly negative meaning to this word,

I have found it difficult to find an English word to directly translate this meaning. Thus, I have preserved the Arabic word within brackets in the translation. This decision meant that I have already identified this word to hold a significant meaning, which is a step further from translation. In other words, by translating the data I have already started the analysis and made decisions on what sounded significant.

3.1.1. **Open coding:**

Charmaz (2014) encourages researchers to maintain an open mind to data at first stage of analysis, she emphasises the importance of letting new ideas emerge without applying any form of theory to the data. She invites researchers to code at this stage using gerunds, an attempt to remain connected to the raw data by seeing actions rather than topics. This will prevent the researcher from focusing on the participant or automatically assigning a type to this person, which may colour the data accordingly, however; by using action language the researcher will maintain vigilance for any changes in events or opinions.

3.1.1.1. Line-by-line coding:

To achieve the purpose of initial coding, which is remaining open for other analytical possibilities, I have focused on two main tasks while analysing the transcriptions: 1) using action language for the codes, 2) maintain a stream of note taking while analysing. The system I used for this purpose was to divide the page into three columns; I dedicated the left column for initial codes, the middle for the raw data which would be highlighted, and the column to the right which is for

analysis notes. The initial codes were written using action language, while the notes were written in a reflective language (Appendix 8 Example of the analysis process- line by line coding). By reviewing the raw data I focused on looking for the code, and also on documenting the ideas that this data would spark. This exercise allowed me to maintain a string of thought throughout the analysis, and to document any similarities, contrasts, or possible new ideas.

Charmaz (2014) describes the use of sensitizing concepts at this stage of analysis in contrast to the more classical view of grounded theory of a blank page. These concepts are described as background ideas that are inevitably embedded in the researcher's discipline, thus; the use of these sensitizing concepts could in fact provide a starting point in the analysis, instead of conclusions.

My standpoint as an OT provided me with different assumptions; such as what constitutes family centred approach, empowerment of parents, and the definition of EI. These concepts were initially present during data collection, and in acknowledging them prior to the first phase of collecting any data I have attempted to keep an awareness of these assumptions while looking at the records and observing sessions. However; these concepts did work as signposts in guiding me to dig deeper or return to a specific set of data. Later in the second phase of data collection, and after conducting an initial analysis of the field notes and records, my assumptions crystalized into guiding concepts; or as termed in the literature (sensitising concepts); which directed the process of comparing data and deciding what to ask in the interviews.

An example of this process is the assumption that family centred model dictates assessing the daily routine of the family to establish where there is need for intervention, this assumption came from my education as an OT where the main elements of the family centred model were discussed, one of which was the integration of the intervention within the daily routine of the family. In the first phase of data collection I have looked for the documentation of this assessment within the records of the EI, I expected to see some reference to the daily routine of the family within the assessment form, but this was not included in any of the records. I have also observed one assessment session with the EI team, and being aware of my assumption I have looked for questions that pertain the daily routine of the family, however; this was briefly discussed with the parent by the EI team but the focus was on the development of the child rather than the interaction and different roles within the family. To pursue this assumption further in the second phase of data analysis, I have asked the therapists about the assessment process within the EI intervention to establish if any of them considered the daily routine of the family. The result of this process was the absence of an assessment of the daily routine of the family, which challenged my initial assumption that a family centred model requires a focus on the daily routine of the family, although my assumption is based on a theoretical understanding of the family centred model this process verified the existence of a gap between the theoretical model and the application of it in reality. This gap will be discussed under the theme (Early intervention within the Jordanian culture page number 151) under the findings from phase two.

3.1.1.2. Note taking and reflective memos:

The methods I used to maintain this awareness of my role varied depending on the stage of the analysis. Initially I used audio recordings to document my reflections, which was particularly helpful after each interview or session. I also divided my documentation of the procedures of the study into a narration of the steps, and a string of memos and comments that are reflective in nature to track my thought process. And during the analysis I included a column to each transcription where I documented analytical notes on the data including possible comparisons or links to other data, and used the header and footer of each page to document reflective memos (Appendix 8 Example of the analysis process- line by line coding).

To understand the language used by the occupational therapists and parents who participated in the study, I attempted to construct codes which would combine what was expressed by the participants with my own understanding of these expressions. Grounded Theory Analysis emphasises the role of language in what is coded and how the researcher formulates an understanding of these codes. The acceptance of the researcher's limited ability to completely isolate themselves from the data, and thus their un-denied influence on how they see and understand the data is acknowledged rather than denied (Charmaz, 2014).

In this aspect, my role as a researcher who worked as an OT within an early intervention programme in the past is carefully studied. There are possible effects of this experience on the construction of codes and ultimately producing findings. The influence of my understanding of what the participants say and how this will

influence the analysis could be perceived as either positive or negative. Only by being aware of these influences and acknowledging them would this understanding be used positively rather than constituting bias.

The following table (

Table 2 An example from the analysis process - forming categories) presents examples from the analysis process, in the first column (open code) the line-by-line coding is presented, each code is written in gerunds a method recommended by Charmaz (2014) to reflect the data and exclude any influence from the participants' attributes or personality. The second column represents the focused codes which are codes seen in other interviews, thus constant comparison is achieved between interviews. The third column gives the main category under which the codes fall, these categories helped lead to forming the themes and subthemes at a later stage. The final column shows the source of data from which each open code originated from, the full list of codes and categories can be seen in (Appendix 9 1st phase Codes to categories table).

Open Code	**Focused code**	**Category**	**Data type**
Giving comments	Informant	Parent's role in session	OT session
Encouraging child	Cheer the child		OT session
Using "behavioural modification" as term	Jargon used	Professional language and terminology	Parent-team meeting
OT Giving an example to clarify	Simple language		Parent-team meeting
Mother not understanding	Lost in translation		Parent-team meeting

Explaining to mother the goal	Jargon used	EI team role	Assessment session
Interacting with mother	Lost in translation		Assessment session

Table 2 An example from the analysis process - forming categories

3.1.2. Generation of themes:

The transition from categories generated directly from raw data to themes representing the voice of the participants was challenging, while the categories I have generated did present the observations and expressions of the perspectives of the participants, they were very descriptive and lacked the depth necessary to understand the data, at the same time the categories were collecting similar data sets, but I needed to generate themes that provide an in-depth understanding of the data and allow contrasts and comparisons between views. To achieve this I used mind maps, where I have compiled categories that discuss one topic under one main group, then proceeded to draw links that represent similarities or contrasts, at the same time I used notes to document the different descriptions within each group (Appendix 10 Phase one analysis process – categories to themes). These produced subthemes which were then grouped under main themes and are discussed the following sections as the findings from phase one and two.

3.2. Phase one findings:

The resulting themes from phase one were generated from the categories which emerged from the data, those categories that were more common and presented a

true reflection of the data were expanded into bigger categories, this process of expanding and merging categories continued until three main themes became evident: 1) Language used in sessions, 2) Location of parents, and 3) The role of the parents, all are represented in the following Figure 6: First phase resulting themes:

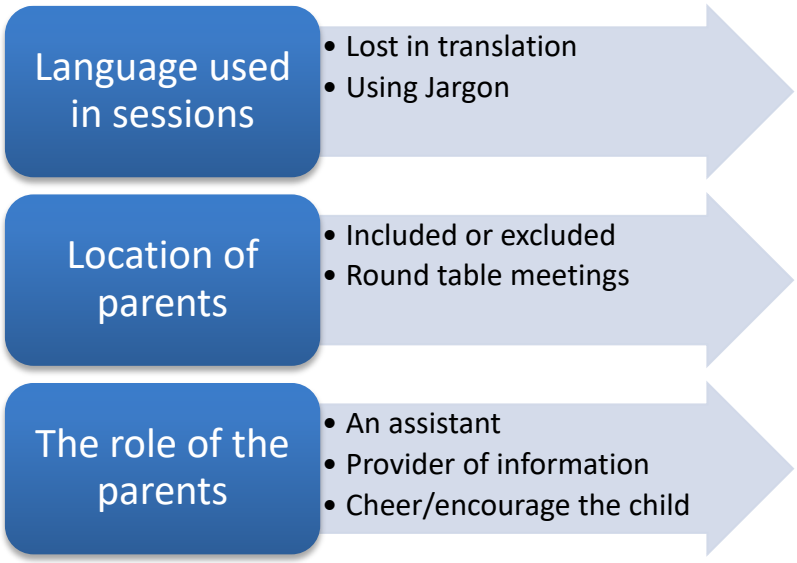


Figure 6: First phase resulting themes

The presentation of the themes for this phase will include segments from the observations I have made during the observations of sessions, as well as notes taken while reviewing the EI records. To distinguish these segments from the description of the themes I will use different font in italic, and indicate the source of each segment, as well as the date when these observations or notes were recorded.

3.2.1. **Language used in sessions:**

This theme described the language used within sessions and the records. The focus placed on language revolves around the communication between the therapists

and the parents. While this is an essential aspect of the therapist-parent collaboration, the language used during interactions between the two parties varied depending on the setting or the aim of the meeting. The variation was in the complexity of the language as well as the type of language (i.e. English or Arabic), thus this theme was divided into two subcategories; lost in translation, the use of Jargon.

3.2.1.1. Lost in translation:

The field notes and records of the EI programme showed the use of two different languages when communicating or documenting the intervention. While English is used in the records by the team to document the assessment, EI intervention plan, and progress notes, Arabic is also used to document formal communication with the parents, such as the set of rules of the programme, the schedule of the sessions, and the EI contract which is signed by the parents.

At the same time, Arabic is used to communicate within sessions and parents-team meetings, and the various comments or recommendations by the team to the parents are all documented in Arabic.

> "a form for the meeting was also available, the language used is Arabic. This form include the goal of the meeting with the main point stated by each member of the team and their recommendations"
>
> Team-family meeting 22-12-2016

This use of the Arabic language in documenting the meeting was observed to help the parent read the recommendation and sign it at the end of the meeting,

however; when I reviewed the EI records for each child I noticed the use of the English language mainly in documenting the intervention plans and progress notes by the physiotherapists and occupational therapists, I did note also that the documentation from the speech and language therapists and the special education teachers (who are the other members of the EI team) were written in Arabic. This meant the EI records used two different languages to document intervention plans and progress notes, this also showed a clear separation in the planning process between the team members as each staff wrote their own plan and notes using different templates and language.

The use of Arabic language in communicating with the parents continued during the assessment session, as the team used Arabic to ask the mother questions and communicate with the child, but they used English when they discussed the child with their colleagues in the professional team. Although I did not have the chance to verify if the mother understood English or not, I did observe her confusion at this stage which might indicate she did not.

> "the team discussed the child after each activity using English, and the mother did not seem to understand. The OT did try to explain what she was doing to the mother using simple Arabic, but the rest of the team did not."
>
> Assessment session 2-1-2017

The use of the English language to communicate between the team members could stem from two possibilities: 1) the difficulty in using professional terms translated

into Arabic when the staff used English language in their formal training, thus; they used English terms for easier communication with their team. 2) the team did not want to share the discussion with the parent yet as they did not finalise the assessment but they did need to communicate together during the assessment, and so they used English language to maintain the privacy of their discussion in front of the parent.

My own experience suggested the first possibility as I reflected on the professional training for the team which was mostly in English, I also remembered the difficulties we faced as a team in translating professional terms to easy Arabic terms. However; to verify my assumption I did ask the occupational therapists I have interviewed in the second phase about using English language and they did confirm the first possibility, commenting on the difficulty to communicate in professional language in Arabic when they did their training in English. This will be further discussed in Chapter 4 when I present the findings from the interviews with the therapists.

Reflection: *I look back at my own practice and can relate to this [using translated terms], it was very difficult to discuss technical issues using Arabic when our professional programmes were taught all in English*

This variation in what language to use both in sessions and in documentation is

indicative of two issues, the challenge the therapists face in translating terms they learned in English into a simplified Arabic, and the challenge the parents would face if they choose to read their child's file or participate in some team discussions which would limit their ability in participating actively in their child's intervention.

3.2.1.2. Using Jargon:

Throughout the different interactions observed between the team and parents, the therapists used different levels of languages. During the sessions, the therapists were careful to use simple and clear words that were easily understood by the parents, they were clearly attempting to make sure that the parents understood the complex therapeutic terms by trying to break these terms into simple words. It is important however to highlight that the success of these attempts seemed to depend on the personal skills of the therapist, for example; during one session, the OT could explain the way the child uses her hand to reach for the toy but within the boundaries of the spasticity in the muscles.

> "the OT explained to the father the current level of performance of the child […] the OT used a demonstration for reaching, and simple terms such as (bend, hold, open hand)"
>
> OT session 15-1-2017

Memo:

Following this session the OT approached me to ask about her performance during the session, she was my student when she was in the university and still felt the need to verify her practice with me, it might be that her performance in the session was impacted by my presence!

While during one parent-team meeting, another therapist could only use jargon and professional terms to describe why the child was showing negative behaviours during therapy.

> "throughout the meeting the team members used jargon and complex language terms to describe their work. Two times the mother asked for an explanation or clarification, Arabic was used mostly but most of the terms used were translated terms from English and are profession specific, so would only be familiar to the staff, such as (Ta'del Alsolook – تعديل السلوك) behavioural modification"
>
> Team-family meeting 26-12-2016

In the first instance, the parent clearly understood what the therapist was explaining by repeating the concept using their own words. However; in the second instance the mother said she could not understand and requested a repetition. The therapist in this case attempted to explain again but still did not manage to use lay terms which resulted in the mother showing clear signs of frustration.

The use of professional terminology when talking to parents is acceptable if the therapist explains the meaning of these terms, but in these instances I observed

the therapists were using complicated professional terms to explain the progress of the child. The parent who asked for an explanation and did not get one assumed a passive role in the remainder of the meeting.

From what I observed through the sessions and meetings, and what the therapists and parents talked about, the use of terminology in communicating with the parents could be another way the therapists use to assert their role as experts. They are communicating to the parents that they have knowledge beyond the abilities of the parents, and this knowledge is related to the child's situation, thus the language that the therapist used serves to reinforce the idea that the therapist is in a position to know what is best for the child.

3.2.2. **Location of parents:**

The physical location of the parents within the different sessions I observed continued to catch my attention. There seemed to be an unspoken rule regarding where the parents should sit in relation to the child, depending on their role within the session. Throughout the observation notes I took, I have documented repeatedly the layout of the session, and when analysing these notes, I noticed a theme to describe this layout. This theme has two parts:

3.2.2.1. Included or excluded:

The parents were directed as they entered the session room to sit in a specific location depending on the activity of the session, I observed this in two OT sessions and one assessment session. During the assessment, the mother was asked to place her child on the mat in a specific spot, the therapists then took their places

around the child to form a circle that included the mother.

> "the mother and child were asked to sit on the mat with the mother behind her child, the team sat in a circle around the child, they all could observe the child's face, but the mother could only see the back of her child"
>
> Assessment session 2-1-2017

This location was different within the therapy sessions, in one session the parent was directed to sit at the corner of the table, placing the child next to her but with some distance to separate them, while the therapist sat facing the child and closer to him. In the second session, the parent was asked to place his daughter on the therapy mat and to take a seat at the back of the session, the therapist then sat on the mat next to the child and proceeded with the therapy.

> "the child was seated on the mat in front of a wall mirror with the OT sitting behind her, the father sat on a small chair at the back of the room […] he did not at any point work directly with the child but continued to sit to the back"
>
> OT session 15-1-2017

The manner in which the therapists directed the parents to where they should place the child and sit was using verbal commands or a gesture. In the assessment session, the mother was meeting the team for the first time, and so the command given to her was clear using words and one of the therapists directed her to the mat. However, in the therapy sessions the therapist used a gesture and one word to simply point to the location where they wanted the parent to sit.

The significance of the parents' location during the sessions lies in the indirect message it sends regarding the role of the parents. Their presence in the session is important but within the boundaries set by the therapist, for example, sitting in the corner away from the child indicates that the role of the parents is to observe not participate. At the same time the therapist who is indicating verbally or using gestures to the parent to sit in a specific place is in fact sending a message of who is in charge of the session.

This type of communication and role assignment is plainly seen in the assessment session, when the parent is meeting the team for the first time. Here no roles are assigned yet, but right at the beginning of the assessment the therapists direct the mother to place her child on the mat and sit back. This is followed by the team focusing their attention on the child and only addressing the mother when they ask her a question. So this interaction is how the therapists send a message of what they expect from the mother; "bring the child to us and sit back and let us do the work".

> "the focus of the staff was on the child, the mother volunteered information at time but the staff only nodded and continued working with the child"
>
> Assessment session 2-1-2017

While this instance is only one that we couldn't possibly use to generalize, similar behaviour was observed in the other therapy sessions. The difference here is that the therapists and parents are familiar with each other, so the 'routine' of placing the child on the mat and sitting to the back is already established, and thus the

roles of who is doing the therapy and who is observing is set.

One observation noted during the assessment session is the reaction of the mother, when the team met the mother at the door of the room. She expressed her hope that they would answer her questions, and help her figure out how to deal with her child at home, the mother spoke of how she went from one centre to another with no results. After this the team directed the mother inside the room and asked her to place her child and sit back. Following this the mother became less talkative, she reacted to the directives of the team by abandoning her curiosity (which was evident at the start) and assuming a "passive role" in which; the mother only spoke when asked by one of the therapists, and at the end of the assessment she waited for the team to give her the results.

> *At the start of the assessment session:* "the mother explained that this is exactly what she needs because her child seems to not be progressing according to her age but previous centres did not seem to give the mother information on the development of the child"
>
> *At the end of the assessment session:* "the mother sat behind the child and answered the questions of the team, she observed how the team assessed her child, but did not volunteer information, and responded only when spoken to […] at the end of the assessment the team gave the mother their decision"
>
> Assessment session 2-1-2017

This change in reaction could be due to different reasons, such as the team using

English language to discuss the situation of the child, or might be the mother's way of letting the team focus on their task. In any case, the combination of the language used, the location of the mother, and the authoritative way the team talked to her could be the cause for the passive response the mother showed by the end of the session.

3.2.2.2. Round table meetings:

The therapists followed a different procedure during the parent-therapist meetings. They had the room prepared which included a round table setting, they asked the parent to take a specific seat and then each therapist sat around the table. The specific seat that the parent took placed the leader of the team to her left side, and the remaining therapists faced the parent. Although the table was round but the team arranged their places so they would all face the parent.

The emphasis given to the location of the parents and the therapists stemmed from the type of participation this location allowed the parents. In the sessions the parents were sitting either away from their child or behind the child, this placed the parents in a limiting position to physically interact with the child, and thus indirectly restricted their participation in the session.

On the other hand; during the meetings, the location of the parent and team around the table but in a way facing the team also suggested a specific type of interaction, one where the parent was not part of the team but rather is facing them, or in other words placed the parent on one side of the discussion and the whole team on the other.

> "team and mother and child sat around a circular table, the child was next to the mother, the seat on the mother's other side remained empty, the table had the meeting's forms, the team's reports, and some paper and colours for the child."
>
> Team-family meeting 26-12-2016

Although the meeting took place in a room with a round table, which is generally used to place people on the same level of power, the team arranged the meeting to indirectly reflect their expert status. This was observed in leaving the seat to the left of the parent empty and choosing to sit clustered in front of her, and also by leaving the table empty in front of the parent while they had already placed papers and pens in front of their own seats. Whether this arrangement was done on purpose, or was a mere reflection of how the team perceived their own role in the meeting is unclear. The observations indicate that the team did put an effort to include the parents in the meeting on an equal ground, by using the round table, however the other arrangements point to a different reality.

The observations also noted the direction of the conversation during the meetings, the leader of the team asked the mother to start the meeting by explaining the strength and weakness points in her child, then each of the attending team members gave a summary of what their intervention goals are, and how the child is progressing.

> "the mother was asked to describe the strength and weakness points of her child, […] each EI team member started to describe the strengths and

> weaknesses of the child (from their profession's point of view) then stated the goal for the next month.
>
> Team-family meeting 22-12-2016

> "the mother was invited to describe the strength and weaknesses of her child from her point of view, the mother didn't understand the meaning of strength and the OT gave her an example to clarify"
>
> Team-family meeting 26-12-2016

This type of communication allowed the parent to get a complete picture of their child's progress. It also gave the parent the message that they were there to receive the reports rather than discuss the plan. The meeting did not include a discussion of the intervention goals, each member of the team stated the goals they are aiming to achieve, and the parent was asked if they had any questions. This impression was corroborated by parents who referred to these meetings as "re-assessment" during the interviews in the second phase of data collection. In their reference they indicated their role in these meetings, that they were there to listen to the re-assessment, they were not there to give their input and participate in the discussion.

3.2.3. **The role of the parents:**

This theme describes the observed role of the parents during different types of sessions, it consists of three subcategories:

3.2.3.1. An assistant:

During the OT sessions, the parents were observed to provide assistance to the

therapists when requested, this assistance included; participate in the play if a third player was needed, prepare activity tools, and assist the child.

In one of the OT sessions the parent was seated at the table with the child and the therapist, her position was next to the child while the therapist faced them. The mother was instructed to help in the activity by preparing the colours and arranging the materials, she then participated in the activity. This role was guided by the instructions from the therapist; the mother was not involved in the preparation of the session which was clear because she asked the therapist about the activity.

> "the mother was seated to the side of the child and encouraged the child to work, at certain points the mother was included in the task, other times she was excluded and became occupied with her phone. […] through the session the mother was acting as an assistant, she took cues from the OT when the child was distracted and encouraged her to focus."
>
> OT session 19-12-2016

Although the parent's participation is important, it does not indicate an active role in the session. The parent was assisting the therapist in the sessions which is a lower level of parent participation, compared to a parent who is involved in the planning of the session, and who is the one leading the activity with the child.

3.2.3.2. Provider of information:

The second role of the parent was to answer questions about the child's performance at home, this is an important and positive role. When the parents are

giving information about their child they were observed to also ask questions that related to how they could help their child at home. This type of communication is essential especially when the programme does not give the therapists the opportunity to make home visits.

> "the OT asked the mother for some information about the child's level of performance at home or her abilities. She discussed the child's ability to use scissors at home, and whether she is given this opportunity, the mother explained that she does not yet feel confident to give her child scissors. "

OT session 19-12-2016

The therapists were keen to collect information from the parents, their emphasis on this aspect showed their awareness of the importance of follow up at home. In the observed sessions the therapists gave recommendations to the parents regarding techniques to enhance active participation of the child at home, however, these recommendations were given verbally, which might be soon forgotten by the parents.

During the team-parent meetings one mother described her own method of documenting any training or recommendations she received from the therapists, using videos or writing their own notes after the session. This indicated the importance of these recommendations to the parents.

> "the mother also asked to be trained on some of the exercises that she saw at PT [physiotherapy] session so she could use them at home, she

> explained that she records (using video camera on her phone) the exercises she finds helpful so she could copy them at home."
>
> Team-family meeting 22-12-2016

3.2.3.3. Cheer/encourage the child:

During all the sessions the parents were observed to give constant encouragement to their child. They gave verbal compliments when the child was working hard, and directed the child to pay attention when needed. This role was the most evident during the sessions, and the parents did this role when they were sitting in the corner of the room.

In one session, the parent was giving their child continuous encouragement, and at one point he commented that he "comes to the session just to cheer her [his child]". This comment was given with a note of sarcasm from the parent. The context for this comment was related to how he was getting phone calls and needed to leave the session, and the therapist commented to him that he needs to stay in the session.

> "role of father was limited to giving small comments about the child's performance at home and her abilities, and encouraging the child to focus and work with the therapist, he commented halfway through the session that his role is to "cheer the child so she stay focused in the session"
>
> OT session 15-1-2017

This example was indicative of how the parents perceived their role. I use this as a compelling code, which is described by Charmaz (2014) as a part of the data that has a clear significance, and is immediately coded. The parent's comment clearly

shows the way he sees his role within the session, this parent used a sarcastic note because he perceived this role as unimportant. His clear interest in his child's rehabilitation was evident in his behaviour during the session, however; even with this enthusiasm and knowledge he was still asked to sit at the back of the room, this might have been the reason why he used a sarcastic note when talking about "cheering" his child.

> "he did ask a lot of questions related to the purpose of the activities and whether the child can do this at home. He presented an excellent knowledge of the child's abilities and strength points, and he communicated with the child in a very positive manner encouraging her to work hard and pointing out her strength in many areas"
>
> OT session 15-1-2017

In the second phase of data collection I interviewed this same parent, he described his role as being a recipient of services, he spoke of how he tried to be more involved, and was keen to organize his schedule at work so he could be available during the sessions, but complained of the inflexibility of the team when it comes to suggestions. He commented that at the beginning of the programme he thought his role was to be a partner in the intervention, but after the first suggestion he made his role became more passive. This will be discussed in details when the findings from parents' interviews are presented.

3.3. Conclusion:

This chapter discussed the data analysis process, describing the different steps

used to generate themes from data collected in phase one and two, I have used examples of codes and categories to illuminate the analysis process, as well as the use of reflective memos to assist me in the analysis. Then the findings from phase one were discussed as themes, I have described the observed collaboration between parents and therapists in EI, where therapists seemed to use professional terminology in English language both while communicating within the team and in documentation, a feat that reinforced their role as experts who pertained complex knowledge. While parents were observed to take on recipients' role rather than partner, evident by their physical location during observed sessions which was to the side of the room, and their difficulty in understanding professional terms – even when translated to Arabic- or at times their alienation from the discussion when the team used the English language.

The following chapter will present the findings from phase two, which included resulting themes from interviews with the parents in section one of the chapter, and interviews with the occupational therapists in section two. The expert-recipient relationship will be described further from the perspectives of both parents and therapists, with more details to explain the role of each group, their expectations from the collaboration, and the challenges they faced.

4. Chapter Four: Phase two Analysis and Findings

This chapter will present the findings from the second phase of the study, this includes 1) interviews with parents of children who uses EI programmes, and 2) interviews with occupational therapists who worked within EI programmes in Jordan.

4.1. Analysis process:

The following section will focus on detailing the analysis process used for this phase, the participants' details for each set of data, and procedures used to generate the main findings from data resources. While the analysis process followed the same procedures for the interviews with parents and occupational therapists, each set of interviews were analysed separately, thus; the findings are also presented separately.

4.1.1. Participants' details – Interviews with parents:

In the second phase of the study seven parents were interviewed, they were approached at the EI programme and the interviews took place after the parents finished their children's therapy sessions.

The following Table 3: Participating parents' information gives some details gathered about the participants to establish how long they have been in the programme. It was important to interview parents who are at different stages in

the EI intervention, to collect data from parents who recently started the programme, and others who had been in this programme for more than a year. It was also fortunate to meet with parents who were concluding the programme to have an overview of their experience.

Participant*	Gender	Child age	Duration within EI
Majd	Male	5 years	2 years 6 months
Ihsan	Male	5 years	1 year
Lana	Female	2 years	8 months
Maya	Female	1 year 7 months	7 months
Noor	Female	5 years 6 months	2 years 3 months
Faten	Female	5 years 11 months	4 months
Yara	Female	5 years 6 months	1 year

* Pseudonyms are used throughout.

Table 3: Participating parents' information

4.1.2. Participant's details – Interviews with occupational therapists:

The interviews with the occupational therapists took place after the invitation to participate in the study was published by the Jordanian Society for Occupational therapists JSOT. As discussed in chapter two the process of recruitment focused on ensuring participating therapists did in fact work within an early intervention programme, the confusion regarding early intervention work in Jordan (discussed

in Chapter one) meant there were centres which did not necessarily include a programme but provided services to all children in different age groups. Five occupational therapists were interviewed either in a neutral location or at their work place depending on their preference. The following Table 4: Participating occupational therapists' information highlights the clinical experience of each participant:

Participant*	Gender	Experience in EI
Reem	Female	3 years
Hana	Female	2 years and 6 months
Bayan	Female	10 months
Lina	Female	6 years
Amal	Female	10 months

* Pseudonyms are used throughout.

Table 4: Participating occupational therapists' information

4.1.3. Analysis procedures:

The analysis of the interviews began with translating data from Arabic to English, the translation was done as a step within the transcription, and it was an important step to become more familiar with the data. I listened to the audio recordings and translated and transcribed the interviews word by word, and took notes on the specific sections that caught my attention. After transcribing all the interviews, I also transcribed the audio recordings of my reflections, and connected notes and memos to each interview.

By the end of the transcription I used the software Nvivo to generate codes that seemed to be recurring in more than one interview, however this software seemed to limit the number of notes I could link to each interview. At the same time the software prompts the researcher to fit data into codes that were already generated, which seemed to force the data into pre-conceived themes. After reviewing the features of this software I became more certain that using it would put boundaries on the open coding phase, I realised that Nvivo is designed to provide analytical tools for thematic analysis, however it fell short in allowing in-depth analysis which is more suitable for grounded theory.

At this stage I decided to conduct the line by line analysis manually. To do so I have designed a template for the transcription to allow both open coding and note coding. This template placed the transcribed interview in a table with one column to the left which is for initial codes, and another column to the right for analysis notes. At the end of each transcription the reflective memos I documented during data collection are also included, and any new reflections were added at the bottom of the analysis pages (Appendix 11 Transcript with coding and reflective memo - OT).

The method I used for coding was based on colour coding, each line was highlighted in one colour and the code for it is also highlighted with the same colour, whenever a new reflection is added I used the colours to link it to the specific line that prompted this reflection.

The initial codes were written in gerunds as recommended by Charmaz (2014), this method helps in assigning a code using an action language, which would remove

any links to the participant's personality or attitude, thus focusing on what they are saying. The analysis notes were written in nouns to assign a general topic for the data, this helped later in finding similarities within the same interview, and contrasting them to other interviews.

During this step of open coding I was frequently interrupted with ideas or questions that were prompted by the data. This happened when I saw a link between what the participant was saying and data from other interviews. I also saw links with the findings from the first phase. To document these ideas and questions I used the reflection space at the bottom of the page, but also referred back to the set of data which seemed to have the link and reviewed them to clarify how these reflections could be phrased. This practise became more frequent as I progressed in the analysis, and soon I became aware of similarities between the interviews, as well as views that were specific to one participant.

After generating open codes from the transcripts, and noting interesting views that are recurring or prominent, I moved on to comparing the codes between the interviews. This process included viewing the transcripts side by side, and noting codes that were shared between the participants, then focusing these codes into a description of the participants' views, in an attempt to form a sequence of what the participants were saying, I have listed the codes and grouped them under categories (Appendix 12 Analysis process from codes to categories). At the same time the unique views that were not shared by other participants were presented by in-vivo codes (Charmaz 2014) using their own words.

As the codes were grouped under categories I saw more links formed between the sets of categories, I used descriptions to explain the topic of each category which helped me in maintaining a focus on the meanings of the categories explained by the participants. The final step in the analysis process focused on generating themes and subthemes to represent the different categories of codes, I used mind maps to visualise the links between the categories (Appendix 13 Second phase OT- from categories to themes and Appendix 14 Second phase parents - categories to themes), and drew diagrams to explain the relationship between themes and subthemes (Appendix 15 2nd phase OT interview themes), two diagrams were generated (Figure 7: The power imbalance theme, and Figure 8: Theme 1 Categorising parents) and will be used in the following sections to represent the resulting themes.

4.2. Phase two findings:

The findings from the second phase of data collection are divided into two sections depending on the source of data: 1) findings from the interviews with parents, 2) findings from the interviews with occupational therapists. To present these findings I will be discussing each group separately. The main theme: Power imbalance represents the themes emerging from both parents' and therapists' interviews. The following Figure 7: The power imbalance theme is a visual representation of this main theme:

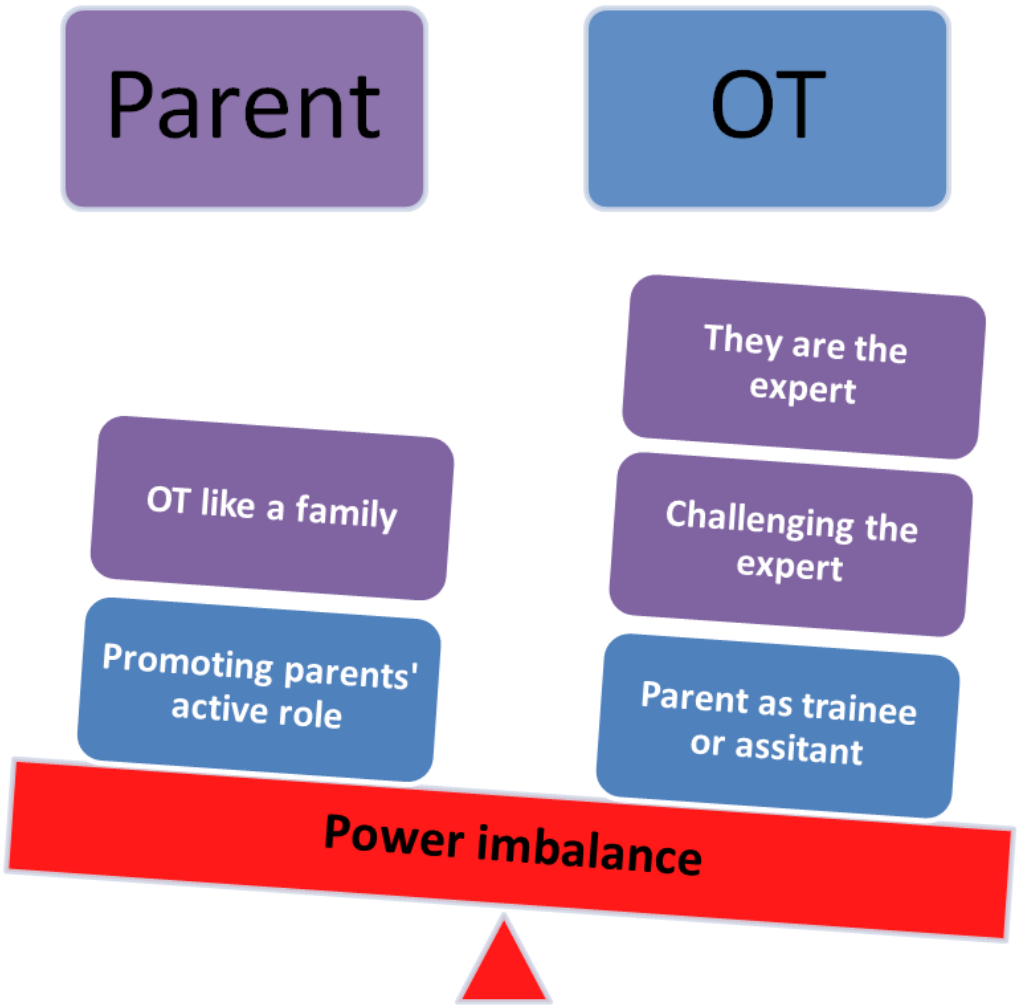


Figure 7: The power imbalance theme

4.2.1. The power imbalance theme:

The interviews with parents and therapists revealed a power dynamic within the parent-therapist collaboration, parents' perception of their role as well as their expectations and engagement in the early intervention programme were expressed within the frame of this power dynamic. On the other hand the therapists' view of their work and their collaboration with the parents was also influenced by the power dynamic within this relationship.

To illustrate this power dynamic and explain how it is currently in an imbalanced state, I will have to present the different themes that resulted from interviews with parents and therapists. The figure above (Figure 7: The power imbalance theme) places the different themes in relation to the power dynamic within the parent-therapist collaboration, it is colour coded to signify which party it is related to, example: the themes coloured purple resulted from the interviews with the parents, while the themes coloured blue resulted from the occupational therapists' interviews. However the themes are positions under the party that gains or exerts power due to this theme, so parents gain power in the collaboration when therapists promote their active role, while therapists exert power when their 'expert' status is challenged.

For the parents their perception of the therapists as experts is essential in how they describe their role and how they expect the therapists to deal within the EI programme. This perception dictates how the parents perceive their involvement in the programme, and how they discuss their collaboration with the EI team. The parents see their commitment in the programme as dictated by the therapists, if they adhere to this power dynamic and meet the expectations of the therapists then they will be fulfilling their role, however when they can't adhere to this role they are blamed by the team and they feel guilt.

4.2.2. **Findings from the parents' interviews:**

In this section I will discuss the findings that resulted from the interviews with the parents. These findings affect the power imbalance between the parents and the

therapists, however here they are presented from the perspective of the parents. The graph presented above will help in showing the links between these findings and the resulting power imbalance.

4.2.2.1. Parents' expectations:

One of the main topics the parents discussed during the interviews was their expectations from the EI programme; they linked this to their understanding of the programme as a whole, and often connected their expectations to those of the EI team.

4.2.2.1.1. "They are the experts":

Throughout the interviews the parents referred to the expertise of the team, and their trust that the therapists would know what is best for the child, they used words such as "experts" and "specialists" to refer to the therapists, and explained that their expert knowledge in therapy qualifies them to make better decisions regarding the intervention.

"we don't have any experience in their work, they are the experts, and whatever they told us they were doing would be the right thing! so we would agree"

Majd (216-219)

This perspective of the therapists' expertise was linked to choosing the intervention gaols The parents expected the therapists to make the decisions based on their knowledge, and when asked if they sometimes give comments to change the focus of the session, one mother responded:

"Yeah, I tell her, but I say she knows better than me, I wouldn't know more about therapy than the therapist"

Lana (312-314)

Another mother responded by preferring not to interfere with "these things" referring to therapy issues, and explaining that the therapist is the "specialist".

"I don't really interfere in these things, I just, you know she is the specialist"

Lana (321-322)

This view of the therapists as experts who know what should be done underlines the expectations of the parents, they enter into the EI programme expecting the therapists to make the decisions, and trusting them to choose the correct intervention goals. However; when this same parent was asked if they always agreed with these decisions the parent gave this example:

"like the other time, I told her that we have been focusing for a long time on sitting and I want my child to start standing, […] the therapist did add exercise in the session to help my child stand, and to help her sit, turn and stand, she did include standing, but I don't really interfere in these things"

Lana (314-326)

In this example we can see the parent identifying her own priority, and seeing as this is different from the therapist's focus she does comment on it, and the therapist does adjust the session accordingly. What is interesting is the mother's

repeated emphasis on her preference not to interfere in these issues, she perceives her comment as interfering with the "expert" and so she clarifies that she does not do this.

The expectations of the parents toward their level of involvement in the programme were also discussed, they expect the therapist to take charge of the intervention, and so when the therapists inform them of the goals or details of the intervention the parents see this as being involved.

"for the occupational therapy, she told me (I'm preparing her [child] now so she could dress independently, or strengthen her right arm) so they did involve me"

Ihsan (74-77)

This involvement includes being informed of the long term goals of therapy, which involves making decisions regarding the child's mode of transfer at school in the future, which equipment to buy, and which school the child would go to especially in terms of accessibility features. The parent still accepts the therapist's decision as correct even if the decisions impact directly on the families' financial situation. The following example shows this level of involvement:

"the physiotherapist he did involve me, he would say (our goal now is to improve her gait using the walker) even he told me that he is preparing her to use crutches so that when she starts school she will be ready, and he did talk to me about this"

Ihsan (70-74)

At the same time the parents perceived their own involvement to follow up by doing therapy at home, this includes learning what exercises to do, and asking questions to clarify how to follow up. The parents expected the therapists to give them directions and to train them, they perceived this as part of the expertise of the therapist, and thus it almost resembles a prescription for medication from a doctor, they need to do the exercises the way the therapist requires and as frequently as ordered.

"you know she is the specialist, so I can for example ask her questions, like what should I do for her legs at home, and she would tell me (at home you have to be careful, you need to do these exercises or that exercise) so that is enough for me"

Lana (322-327)

4.2.2.2. Parents' perceived role in EI:

The parents' perception of their role in the Early intervention was revealed directly through their answers to a question in the interview "what is your role in the programme?", in response the parents used adjectives to explain this role ranging from "trainee" to "recipient". At the same time the parents gave more detailed descriptions of their role in the programme throughout the interviews, using examples from sessions or encounters with the therapists when they discussed other topics such as how to plan the intervention or follow up at home.

The perceptions of the parents towards their role in the EI programme showed some confusion towards their understanding of their role, an example of this is how this parent explains how the therapist "involve" them in the intervention:

"for the occupational therapy, she told me (I'm preparing her [child] now so she could dress independently, or strengthen her right arm) so they did involve me"

Ihsan (74-77)

This perceived role here includes being informed of the priorities of the intervention, and in this parents' opinion this constitutes involvement. Thus; the variations in the parents' labels of their roles and their descriptions of these labels are discussed here.

4.2.2.2.1. Trainee, assistant, or recipient at the EI:

The parents in the interviews were asked to label their role within the EI and within the sessions, their answers ranged between trainee to assistant, with variations in the descriptions for this role. They used examples of what they did within the sessions to explain such variations. One of the parents gave this answer:

"I assist the therapist, recently she [child] doesn't like to sit except on my lap, she gets scared from the surroundings so I comfort her"

Lana (143-145)

The use of the word (مساعد- Mosa'ed) in Arabic indicates help or assistance depending on the context, the differentiating factor is whether the act of

helping/assisting is done within an informal or formal setting, and in this case the mother described her action within a formal context indicating the use of this word as assistance.

The underlying meaning of the word (مساعد assistant) indicates a hierarchical relationship; it is defined as (a person who helps someone else to do a job or who holds a less important position in an organisation) (Cambridge 1995). By using this word to describe her role the mother indicated a relationship where she refers to the therapist for guidance and directions, then follow them to make the work of the therapist in the session run smoothly. The parent clarified her role as follows:

"she [therapist] taught me how to help her [child] use her hands, or how to play with sand or water, and the way to follow up at home, like how to put my child in the shower and let her play with the water"

Lana (149-153)

Another parent responded to the same question by explaining the procedures that typically happen in the session, in her words she saw herself as a trainee:

"the therapist shows me what to do and I do it in front of her so I learn, this is how the session goes so I can learn the therapy and do it at home"

Maya (160-162)

"I think I'm a trainee, because I really had no experience in this at all when we started, so I had no information, I mean I tried and still trying to learn more, I read on the net and watch videos on YouTube, but I needed someone to teach me and help me learn, so I think I am a trainee"

Maya (262-266)

This parent clearly links her role as a trainee with the level of knowledge and experience in therapy she did not have at the start of the intervention. Her view reflects an acceptance of referring to the therapist as the expert who is to provide her with the needed training and information and she appreciated this kind of relationship by expressing her satisfaction with the EI programme:

"they help by explaining to me her situation in much more clear way and a better way, and they helped me in how to deal with her and how to help my child, and how to make her stronger so how to follow through with therapy"

Maya (56-60)

The parent continued to reflect on the success of this collaboration, she described the impact of the EI on her child and on her family's daily routine in positive terms:

"it is now something that is done automatically, and this the whole family, her father and sister and me, we all know for example that we need to address her from the left side so she would be more aware of it, and even her grandparents know this and know the right way to deal with her so they can help her"

Maya (104-109)

Another parent gave emphasis to the importance of listening to what the therapist would tell her so she could follow up at home, although she did not give a specific word to describe her role, the way she explained it seemed to imply a role of a

trainee. What was significant in this parent's reply was her phrasing of the description, she used *"have to"* and *"the same way"* to emphasise how important it was to adhere to the instructions of the therapist:

"I have to listen to everything and apply it at home, this is important, so I watch the therapist and what she does at the session and then do the same at home, the same way"

Noor (121-124)

The parent gave an example from one session to explain how the therapist taught her therapy which she later would do at home, notice how she recounts these instructions almost like a medical prescription:

"the therapist taught me how to help my child, you know, what way should I grasp her when she is walking, and how to encourage her, so he told me to do the exercises at home, like 4 times, so I would know what to do and how many times"

Noor (195-198)

The way this parent refers to her training reflects her perspective of the collaboration with the therapists, she receives training and instructions in the session, then applies them exactly *"the same way"* at home and according to the frequency decided by the therapist. Later in the interview the mother mentions this process of collaboration to show how her child has actually improved, thus linking this type of collaboration to the positive improvement she saw in her child:

"he would first show me what the exercise is, then I would repeat it in front of him like 3 or 4 times, and then I would do it at home, and after a while

we can see that she is improving so we would focus on something else, so within 7 months she improved a lot, you know she walks alone now"

Noor (203-208)

Another mother agreed with this specific collaboration, she described her role along the same lines:

"In the EI, I'm supposed to attend the sessions and follow the instructions of the staff, so for example the instructions from PT or OT what should I do at home and how to help him, so to follow their instructions at home."

Yara (80-86)

The role described by both parents here is trainee, but it has a certain passivity to it, which is related to receiving instructions and following them to the letter, then linking the success of the intervention or therapy to how well they have followed the instructions at home. Another parent explains this link as part of the instructions given to her by the therapists:

"they tell me that I need to do the same exercises at home, because if we do then my child will improve much more […]now they are teaching me how to do them the correct way, and my daughter is really improving"

Faten (162-172)

This mother had described her role as more of an assistant to the therapist, she pointed out the difficult behaviours her child showed at the sessions, then clarified how she attempts to encourage her child in the session so she could help the therapist:

"I sit with my child and encourage her, I help the therapists and tell them that my child is smart, and tell her she is doing well and I would give her a reward if she works hard in the session"

Faten (154-158)

There are recurring elements here to the general role of all the parents within the sessions. They all agree that they are being trained to follow up at home, they assist the therapist during the session, and they do so by encouraging their children to cooperate with the therapist. Their role relies heavily on the therapist's direction and instructions, by adhering to what they are told their children would progress, in other words their responsibility is to follow the instructions as they were trained within the sessions. It is essential to clarify here that the parents appreciated this type of collaboration and were satisfied with how the intervention progressed, they have expressed their happiness with their children's progress and the general experience of the EI programme:

"I'm really happy here […] you know I have told so many people about this programme, I gave them the contact information and told them to come here"

Faten (320-326)

"It [the EI] is amazing, you know as a mother of course I care for my child, but I need a specialist who would tell me how to do this, like move her in this specific way"

Noor (39-42)

"In the EI programme, I think it was excellent, they really did anything I asked for"

Yara (364-365)

4.2.2.2.2. Parent role viewed as burden:

On the other hand, two parents discussed their role in the EI in a more negative and defensive manner, they spoke of the difficulties they face to be able to attend sessions, and the burden they have to deal with when they are at home.

"our only obstacle now is that me and my wife we both work, so we go home every day and we are exhausted, we have no energy to talk or to do anything else, and we try to encourage her [child] to use the walker at home, and I do some exercises, but we are not doing what we should"

Ihsan (100-105)

Note:

Observation from Parent-team meeting (included the partner of the participant Ihsan):

The parent discussed her feelings of regret and guilt that she took wrong decisions in the past for her child; this was not addressed by the team.

The parent seemed to give a justification for their limited follow up at home, then proceeded to point out the efforts they make to achieve this level of participation, in a way that hinted to the feelings of guilt they have for not being able to do more. As shown in the note above, the parents' partner was observed during one parent-team meeting in the 1st phase of this study, where she also expressed feelings of guilt towards their child's intervention.

"we are participating, whenever there is a session I do come here and learn, even though I should be at work, but I would manage and take some hours off work so I could come here and participate in the sessions, so I can follow up at home"

Ihsan (105-111)

For another parent this defensive manner was linked to frustration with the way therapists placed the blame on the parents. He used a metaphor when he described what the therapists expect from the parents, in Arabic language the metaphor describes the responsibility as a physical load that someone would place on his shoulders (*بيحملونا المسؤولية* Beyhamlona almas'olyeh), This specific metaphor is also used when describing how a person might get rid of a responsibility and burden another person with it. For this parent to use such metaphor it indicates his feelings of frustration towards this role.

*"but here they place this responsibility over the parents [**بيحملونا المسؤولية** Beyhamlona almas'olyeh], they say the parents should cooperate with them, and do the therapy at home."*

Majd (71-73)

The parent went on to explain why this type of expectations from the EI team is unreasonable:

"my work is really time consuming, I return home at 8.30 or 9 so I can't possibly start doing exercises at that hour for my son

Majd (84-86)

The role of parents which includes follow up at home with specific exercises is described by the parents as an order, or more precisely as a prescription for medication. The parents explain how they try to follow this prescription at home, however they also explain the obstacles that challenge them to do so. What is interesting is that the parents give valid points to justify why they couldn't adhere

to the therapist's directions, however they do not mention or indicate how the therapists help them overcome these obstacles.

"our role as parents is to follow up with the exercises at home, so they trained us within the session, and we could do the exercises at home, but we had a problem with the time, the time is not enough, my wife have so many responsibilities at home especially with the other kids, and I return home late in the day, so we can't find the time to do the exercises! we try but there are just so many things we need to do daily!"

Majd (177-183)

This same parent later discussed his past experience with the EI. His child was being discharged from the programme after two and a half years, he described how at the start of the programme their priorities were focused on walking, and discussed the attempts the team made at convincing him of other goals. However, he maintained that had the team dedicated efforts on his priority, and had he worked more at home his child would have achieved this goal.

"I do feel guilty now that if we did follow up especially with the physiotherapy my son will be walking now, but I know we had no time for home programme, and my wife worked, so it was just not possible […] we at the time wanted our son to walk, that was our priority, and maybe it was the wrong priority, it was the most important"

Majd (184-195)

What this parent's interview revealed is the possible result of disagreement or mismatch between the EI team and the parent's expectations, when this disagreement remains without compromise. The most evident result is the parent's feelings of guilt, and attributing the unsatisfactory results of the intervention as his own responsibility. However; looking more closely at his views we can see some hints of dissatisfaction with the EI team, *"here they place this responsibility over the parents"* is one example of these hints, notice how he describes the team's action as shifting responsibility to the parent.

Although these feelings of guilt are linked to the parents' adherence to the home programme, but it could also result from the parent's view of their own role towards their child, and how well they are providing for them, both financially and in terms of taking care of a child with disabilities. However, for this specific parent he seemed to discuss these guilty feelings when he talked about doing the prescribed home programme as ordered by the therapists.

"So I look at my situation and I ask myself should I have done more to my son? you see I sometimes find myself have failed him, I did provide him with his financial needs, you know I have that"

Majd (131-134)

4.2.2.2.3. Challenging the "expert":

Throughout the previous quotes parents frequently referred to the therapists' role as experts or specialists, this was linked to the choice of therapy goals, the prescribed home programme, and the expectations of the therapists. One other

facet of this ‘expert’ authority was revealed when one of the parents spoke of their own relationship to the EI team.

The following anecdote describes what this parent faced when they attempted to give a suggestion to the team regarding scheduling the weekly sessions, the parent gave this answer when they were asked whether they had a role in scheduling the EI sessions.

“to be honest I had a suggestion regarding this [scheduling sessions], frankly there was a misunderstanding regarding my suggestion, like the staff thought I was interfering in their work, what I suggested was related to my situation”

“I asked them to fix our schedule for a whole year so I can fix my work schedule for a year accordingly and I wouldn't have to change the schedule every month! and I told them there are several parents like me”

“the staff refused the idea, so I went to the manager of the centre”

“the manager liked my suggestion and said this is very reasonable, but later I am surprised that the EI team took my suggestion as interfering in their work, and somehow stepping on their toes or something like that, so they took a defensive position and told me that I don't know their work and have no idea of their efforts, so I said this is merely a suggestion if you like it then apply it, if not it is ok, but they shouldn't be this stressed”

“I really did not like the way they handled this, the way they talked was not respectful”

Ihsan (175-217)

Analysis note: this parent and their partner were observed in a parent-team meeting to have made an initiative by video recording exercises in the sessions so they could learn it better, this is a pattern in this parent's behaviour, they want to be active partners in the intervention, and they back this up with suggestions and initiatives.

Despite the willingness of this parent to be involved as an active partner, which is reflected in their interview as well as the observations in the 1st phase of this study, but the parent described the attitude of the therapists as not welcoming the suggestions. What is significant in this example is the attitude of the therapists when the parent gave the suggestion, they did not only refuse it, but they also saw the parent's idea as interference in their own work, they were territorial in their defence although the suggestion dealt with a simple managerial matter of scheduling the sessions. According to the parent the therapists' reported defensive position towards the suggestion centred on the parent's lack of knowledge of their work. In other words the therapists seem to present their position as experts who have knowledge which qualifies them to make decisions in the programme, however since the parents don't have this level of knowledge then they should not "interfere" in the therapists' work. The parent said he was *"somehow stepping on their toes"* which describes how territorial the therapists were when he tried to *"interfere in their work"*.

The reaction of the therapists to this parent's interference did not stop here, when later in the interview I asked this same parent to describe his role in the EI programme, he gave this revealing response:

"I would say that at the start I was a partner in the programme, but after this incident that I just described [making a suggestion] I became a recipient, because you know I felt they were even treating me different than other parents […] it was different than the way they treated me before, and different than how they treat other parents"

Ihsan (225-235)

According to this parent, the EI team who perceived making a suggestion as "interference" in their work, responded to this interference by alienating the parent, they changed their attitude to him, and treated him differently than other parents in the programme. I should note here that the therapists involved in this incident were not interviewed within this study, thus; what we have is the perception of the parents regarding what happened, although this incident seemed to have a great significance to this parent, as they showed frustration and seemed very upset while they described it.

The perceived response of the therapists towards this parent could be described as punishing the parent for crossing the line, an attitude that is patronising and authoritative. What is more revealing in this story is that the parent spoke of the therapists' actions as a group, so they all responded in this way, there were no exceptions, which could indicate that the EI team's authority and 'expert status' is not an individual thing, it is more of a culture within this programme.

4.2.2.3. The supportive therapist "like a family":

One of the topics the parents have mentioned was the emotional support they and their children have received from the EI team, when asked about the main aim of the EI programmes parents referred to providing them with support to deal with their child's situation, as well as preparing the child emotionally to accept their situation.

"it gives me ... you know I was worried about the school for my son, he is now 5 years old, and I'm worried who would accept him, what school would accept him, so here in the EI they prepare you mentally for this and they help you, so now they are preparing my son for school, you know, so they are preparing us the parents psychologically for this."

Majd (40-46)

> ***Reflection:*** *I was surprised by this statement from this parent, as a father he placed a great emphasis on the psychological support he received in EI, I had to confront my own assumption about a Jordanian father, because my assumption was it would be difficult for a man from an Arabic culture to admit needing emotional support, then openly appreciate it! My prejudice is clear here.*

The value of this emotional support was highlighted by the parents repeatedly, and expanded to comparing different therapists based on their expertise in giving this support.

"honestly, they are like another family to me, I spend two hours with them, like the OT I worked with before she was very friendly, the special education teacher is very nice as well"

Lana (380-382)

"the good ones they are more comfortable to talk to, they do not put boundaries or borders for how we talk to each other, I feel they let me ask whatever I want, or talk about whatever I want, and they answer my questions and try to help me all the time"

Maya (124-129)

This parent emphasised the importance of talking comfortably to the therapists, for her it is what makes a therapist stand out, she describes a communication style where acceptance and listening is essential.

This view was shared by the other parents who talked of how easy it is to deal with the EI team, she appreciated their acceptance and not judging her regardless of what she said.

"they are so patient and calm, and easy to talk to, you know you can tell them things and they respond to you, and they don't interpret my words in any negative way, they listen to me positively so dealing with them is really easy, I don't have to worry about what I'm saying and how they will interpret it"

Yara (305-312)

Personal traits that are related to communication such as listening and 'easy to talk to' were emphasised by the parents, such traits in the therapists encouraged the parents to talk and express their emotions, which gave them the emotional support they required. One parent even described the team as *"they are like another family to me"* which shows how comfortable she felt within the team, and how good communication promoted a friendly and close atmosphere for the parents.

The parents gave examples of situations when they needed support from the therapists and received it, this kind of support prompted the parents to describe their relationship with the EI team as friendly and even call them a second family. At the same time the parents discussed difficult situations where they were facing personal or financial issues and have had the team to talk to and give them advice. One mother gave an example of her relationship with the team, while she spoke she was reminded of one difficult situation she went through in the past, and became emotional in the interview while describing how the team listened to her and supported her, when I asked her how she felt she said:

"I felt she really was there for me, this kind of support I cannot forget, my mother in law was with me that day and she also commented that this person was incredible, so she had a humanistic aspect that amazed me, they all are very kind and they feel with us"

Lana (389-395)

What the parent highlighted in her story was the way the EI team have listened to her, although her situation was related to financial issues the team could not help

her with, but they still listened and comforted her, she saw this as something she will never forget, and she concluded by describing the EI team as her family.

"honestly, they are like another family to me, I spend two hours with them, like the OT I worked with before she was very friendly, the special education teacher is very nice as well, even the EI manager who was here before, she was amazing"

Lana (380-384)

For this parent to describe her relationship with the team as being in a family is very positive, it indicates the kind of close relationship she had with them, and the level of support they offered her. The use of family relationship to describe the collaboration with the EI team is also important, within a collectivist culture such as Jordan family is perceived as the closest type of relationships a person could have, at the same time this type of relationship has different levels of respect and closeness that exceeds friendships, which reflects the positive effect the EI team have had on the parents.

4.3. Findings from the interviews with occupational therapists:

The following section will present the findings from interviews with five occupational therapists who work within EI programmes. The interviews with the OT focused on discussing the perceptions of the therapists regarding EI services in Jordan.

Five occupational therapists were interviewed, they all worked at one or more EI programmes for at least 6 months, and the interviews were designed to tackle topics which were discussed by the parents, thus attempting to gain the perspectives of the therapists on the same issues. However, the therapists were also encouraged to express their views regarding the EI field in Jordan, as well as the OT education in relation to EI.

Throughout the interviews with the occupational therapists the main theme prevailing was a categorisation of parents within the EI programme based on their role and collaboration with the OT. The therapists described three main groups of parents; these three groups will be discussing in the following section under the first theme (categorising parents).

The therapists also talked of strategies they used with each group to promote more active participation of the parents in their children's interventions. These strategies will be described in the second theme titled (promoting an active role). The therapists also reflected on the reasons why parents could resist their efforts, this will be discussed under the third theme (Early intervention within the Jordanian culture):

4.3.1. **Categorising parents:**

To illustrate the views of the therapists I will use the following Figure 8: Theme 1 Categorising parents, which shows three categories of parents according to the therapists, as well as their reported strategies to promote a more active role of the parents in EI.

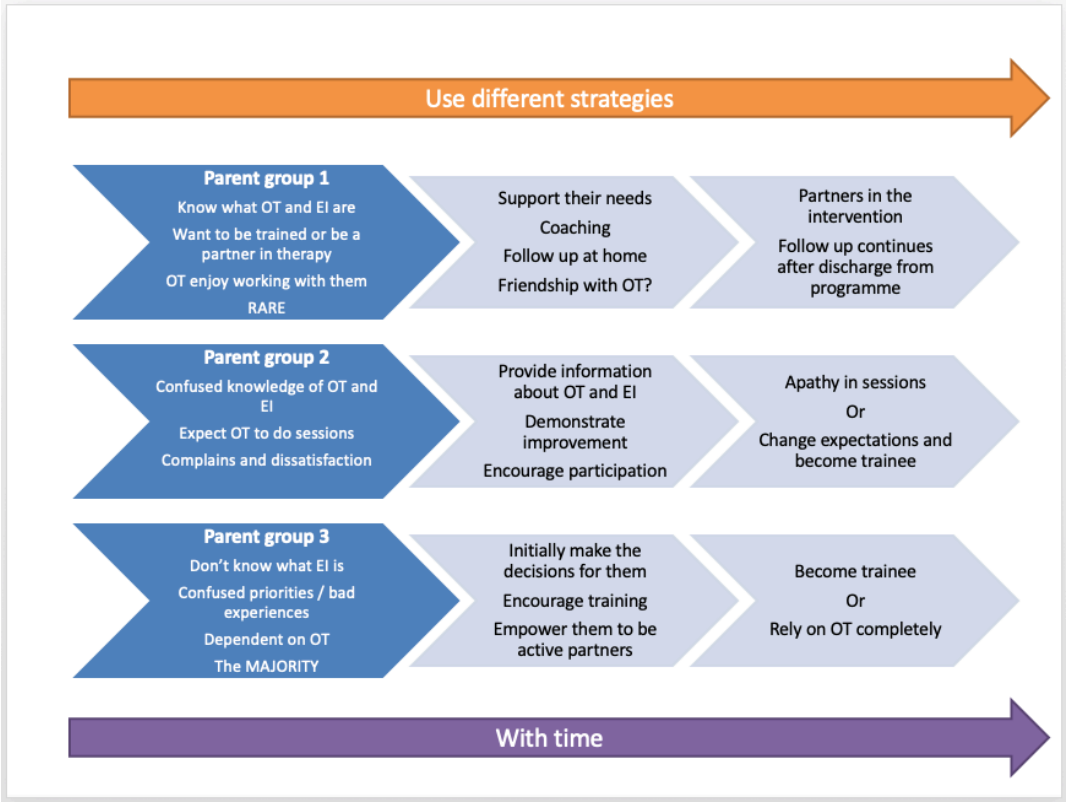


Figure 8: Theme 1 Categorising parents

The therapists presented their role within the EI as helping the child and the family deal with the child's difficulties, they were aware of the impact the family has on the progress of the intervention, and so when they were asked how they dealt with the family they explained this with a categorisation of the families into three main groups, followed by the different strategies they use to promote the role of the family. It was clear that the therapists distinguished between the family's view of the EI at the start of the programme as opposed to their view of the EI after some time, this was linked to the therapists' efforts in helping the family gain information and skills within sessions, but also was linked to the parents' perception of their own role within the EI. One therapist summarised the three groups as follows:

"here in this programme I see all three types, some parents are actual partners, some are more like recipients, and there are those who want to learn"

Bayan (248-251)

This therapist's view is shared by other therapists, who also group parents according to their expectations from the EI programme, highlighting the group of parents who prefer to receive services and sessions rather than train on the intervention.

"there were also people who said (if I want to do the therapy myself I wouldn't come here in the first place! and I wouldn't pay money!) can you imagine this!"

Hana (218-221)

In this description, the therapist talks about the expectations of the parents from the EI team, they want the team to do sessions at the centre, and when they are asked to train so they can follow up at home the parents refuse and emphasise the expected role of the therapists in doing the therapy. This reaction clearly causes the therapist frustration as seen by her exclamation *"can you imagine this"*,. The difference between the expectations of the parents and those of the therapists has a fundamental impact on the collaboration between them, as therapists feel frustrated with the reaction of parents to their efforts in training them or involving them in their children's intervention.

When asked about the possible reasons for the parents' expectations, the therapist gave this answer:

"this is for many reasons: one is that EI is not a very well known service in Jordan and people don't know about it, two the father feel that the child is the responsibility of the mother who due to her educational level or even not the education but like her exposure to life and experiences she doesn't know what to do for her child and where to go"

Hana (324-330)

In this explanation the therapist highlights the impact of previous knowledge of EI on the expectations of the parents, in her view if parents have had some information on what the EI programme could offer then they might form realistic expectations. The therapist also highlights the educational level or *"exposure to life"* as a possible source of knowledge which might help the parent form reasonable expectations from the EI programme.

Another therapist shared this opinion, but was more specific in describing the misinformed expectations of parents, stating that parents would begin the intervention not knowing there are different professionals that could help their child, so frequently parents would expect physiotherapy sessions only in the EI:

"they usually don't have a clear idea of what the programme is, they come here asking for physiotherapy and expecting their child would just take sessions, they do not know that EI has a team of professionals, like each

one in the team could help them in one area, they just come here asking for sessions and usually in physiotherapy"

Bayan (34-40)

In fact, the limited knowledge of OT as a profession in Jordan was discussed by several therapists, they commented on the little awareness of OT they frequently see from parents. Another therapist explained how the work of an OT within early intervention involves a confusing picture for the parents:

"with younger babies because we use toys and play in the session, the parents usually ask me (what are you doing? this is play) so they do not understand that what we do is therapy"

Amal (17-20)

We can see in this quote the challenge this therapist faces in attempting to explain and convince the parents of her role as an OT, because of the nature of the session which involves playing and using toys the parents' might not see this as therapy. Thus in this therapists' narration the parents would be confused and criticise the session *"this is play"*, which results in frustration from the therapist who has to defend her work as more than play *"what we do is therapy".*

When asked what the common reaction of parents is once the therapist explains her role, this same therapist categorised parents into two groups:

"there are two types, some parents who like one mother I explained to her exactly what I do with every toy and what is the purpose, so she really appreciated my work really, the things we do, but other parents they just

stay in the programme because they were told that their child needs OT so they continue even though they don't really get the value of the therapy"

Amal (30-36)

The impact of knowledge is seen again here; with parents who are given detailed information and description of the OT work we can see a change in their reaction, a positive change where the parent shows appreciation of the therapy. However, the impact of knowledge is not guaranteed. The second category of parents according to this therapist would react to this information by continuing the OT programme but without actual active involvement, a passive reaction that could reflect not fully appreciating the OT programme.

The therapists related different perspectives of the parents towards their work, one therapist commented on the initial expectations of the parents, who seem to enter the EI programme with a specific set of expectations:

"at the start of the therapy the parents would say you are the therapist and you know better, or I'm paying so you would do the session"

Reem (333-335)

This type of expectation is more evident at the start of the programme, when the parents still do not know exactly what the EI programme can offer. They come in with their view that the therapists would actually do the sessions hands-on, they also link this type of service to the financial payment the parents give for the sessions, so in a way; and according to this therapist's perception; the parents act as costumers who pay for a service and expect it to be provided to them. However;

the therapist emphasises later how in many cases these expectations would change with time, especially after the therapists explain their role and the purpose of the EI programme.

"but once you work with the child and they see the results and keep encouraging the parent to be active and to do the therapy at home, they do change! I mean some don't change and continue to be distant, but a good percentage do change"

Reem (336-340)

This kind of dynamic is described also by other therapists who explain the way the parents seem to change their expectations after some sessions:

"I tell them (your involvement in the session affect the child, you need to participate, please come closer to your child) so I tell them what their role is in EI and I demand they take it, mostly they do listen and change the behaviour"

Bayan (253-257)

The change of parents' perspectives of the EI and their role in it is prompted here by the therapist, who uses information to clarify her role and that of the parent, then encourages the parents to take that role actively and consistently within the sessions, which in her view would mostly affect a change in the parents' attitude positively.

On the other hand, the therapists spoke of one group of parents who continue to expect the therapists to do all the work and remain as recipients for EI rather than

true partners, this group of parents are described to use the session to make phone calls or even attempt to leave the session all together:

"but then there are parents who are just not there! you know they don't care, they just come in and hand me their child and just sit in the corner looking at their phones or even leave!"

Bayan (359-360)

This passive reaction from the parents seems to stem from more than one reason, as therapists try to use information to change the parents' role, they seem to hit resistance from the parents who continue to depend on the therapists for hands-on therapy, with no active participation in the sessions.

"there are people who come to the session and spend it using their mobile phone! and you try one two three times with these parents to get them involved, you also do parents-therapist meetings, and tell them (we need to work here together)"

Hana (201-205)

The different strategies therapists described to change the expectations of parents, and to promote active participation in the sessions will be discussed in the following theme.

4.3.2. **Promoting parents' active role:**

Throughout the interviews the therapists discussed their role as experts, and the strategies they used to ensure the adherence of the parents, in several interviews

the participants used words to describe their efforts which indicated their perception of their own role, as well as their authority within the EI programme.

"you will have to clarify your point you know, some people would understand what you are talking about, and they accept it, and others they just refuse to accept, so I let them do as they please for now, and focus on her [the parent] own goal, but based on the priorities that I have set you know, not randomly"

Reem (168-173)

In this instance the therapist explains how she appeases the parents by adhering to the mother's priority while ensuring it is one of the therapists' own goals, *"I let them do as they please for now"* indicates the temporary adherence to the parents' wishes to placate them. the word she used in Arabic (نسایر Nesayer) translates as (placate or appease), the language used here indicate the way this therapist perceives her own goals as the correct ones, at the same time she continues to explain how the mother would later begin to accept whatever the therapist deems important.

"in future discussion, in things she wants she would say (the therapist's words are correct) so I would return back to the dressing issues because we should focus on those"

Reem (174-177)

The way this therapist describes her strategy in handling parents who do not accept her authority is revealing. Evidently, this therapist placates the parent to enforce

her own ‘expert status’, she also aims to reach a point in her relationship with the parent where *(the therapist's words are correct)* which could be referred to as blind trust.

This therapist used the term “blind trust” to describe parents who achieve a level of cooperation or adherence to the therapist after some time, she describes what she means by this term:

“I mean some don't change and continue to be distant, but a good percentage do change, they even develop blind trust of the therapist so you could actually add any goals you want to the therapy and can convince them of it”

Reem (338-342)

It is eye opening how this therapist highlights her aim to reach a point where the parents let her “add any goals you want to the therapy”.

On the other hand, another therapist described the progress of a positive collaboration between her and parents as one based on mutual trust, one where she would talk with the parent through the development of goals, then provide them with knowledge about her role and the child’s situation, which would lead to the parent’s trust in the therapist, and possibly more active collaboration in the intervention.

“I think the trust between us changes, the parents might develop more trust after we set the goals together and we discuss them and talk about the child's situation they know the therapist more, especially if they see good

progress, I think parents would become more open after they see development with the child they would initiate more, improve this collaboration"

Bayan (511-518)

There is a difference between these two therapists' views regarding parents' collaboration and adherence. For the first therapist (Reem) her perspective deviates towards a more paternalistic approach to the collaboration with the parent, she sets the expectations of the intervention based on her expert knowledge and expects the parent to follow accordingly. If the parent insist on their own goals for the intervention she placates them while she implements her own goals, anticipating their adherence or "blind trust" to happen once they see positive results. The second therapist (Bayan) seeks a shared level of expectation from the parents, she uses discussions and provides knowledge so that mutual trust would develop as a foundation for the therapist-parent collaboration, thus achieves active participation from parents once they see positive results.

With both therapists we can see how they esteem their expert knowledge as the best tool to use when prompting parents to collaborate actively, but they use this tool differently; one enforces her expert opinion and expects parents to see the value of this expert knowledge, while the other uses her knowledge to enlighten the parents and prompt understanding of the child's needs, aiming to reach a shared understanding with the parents.

The following quote from the first therapist (Reem) follows the same pattern in using knowledge to enforce expert status:

"in fact our work is not just doing therapy's sessions, we have to do awareness sessions for the parents and even more awareness until they are with you on the same path then you can do the therapy for the child"

Reem (547-550)

We can see here how knowledge is used by this therapist to ensure adherence from the parents, the aim is to gain the parents' acceptance of the judgement of the expert *"then you can do the therapy for the child".* While we see a different aim with the second therapist (Bayan):

"I think parents would become more open after they see development with the child they would initiate more, improve this collaboration, they would start to talk more about things I didn't pay attention to, they would lead to more issues that we didn't discuss once they feel they can trust me"

Bayan (515-521)

Expert knowledge is used as a strategy by the therapists to prompt collaboration from parents, but the motivation behind this could be different depending on the view of the therapist. As described above, therapists could aim to assert their expert authority and ensure adherence from the parents, a state where the parent accepts the judgement of the therapist and follow their lead. While in the second case we see a different motivation for using expert knowledge; to encourage and empower parents to give their opinions, and *"lead to more issues that we didn't discuss".*

4.3.3. **Early intervention within the Jordanian culture:**

The interviews with the therapists revealed a perceived gap between the reality of early intervention in Jordan and what the therapists thought of as "ideal". When the participating therapists were asked to describe their role in EI or the role of the parents they mostly used a comparison between reality and ideal EI to illustrate this gap, then explained why such a gap might exist.

"you know the therapist's role in EI is to facilitate the intervention to the family, you facilitate all the resources and information to the parents, so they could provide the actual rehabilitation, the parents, they would be the ones making the decisions of using available resources!"

Lina (150-155)

Here we can see a description of what this therapist thought of as the "correct" early intervention, where the therapist works on facilitating resources and providing information for the parents, who then would use them to make decisions regarding their child's intervention. This perspective was shared by other therapists:

"ideally, the parents would attend the session here and see the exercises I give, what are the activities I'm doing, and how is the child reacting, and based on what they see here they would carry over the rehabilitation at home, you know do these sessions for their child, and the child would progress better."

Bayan (89-95)

The focus of the "ideal" EI is different between these two therapists; the first highlights the importance of providing information for parents which she perceives is the essence of the EI, while the second therapists considers training the parents to follow up at home with the intervention as the most essential aspect. However; both therapists agree that the reality is different from what they expect in the EI:

" but in reality there are different role for the parents, so it is not ideal, so some of the parents would think that the sessions we do here are enough, so they don't do anything at home, they say (my child is taking X number of sessions here so that's enough) and this is not what EI is all about!"

Bayan (95-101)

Interestingly; a third therapist described another "ideal" EI, she discussed a programme where the parents are participating actively in setting the long term and short term goals of the intervention, then the parents keep a monitoring role to oversee the progress of the intervention through meeting the goals.

"when we set the plan with the family we will set the long term goals for the future, we will use outcome measures to test the progress and then we would set the short term goals. This is all with the parents, so they will be able to have a whole picture of their child's situation, and they will then pay attention when we are not meeting a specific goal so they would then work extensively at home to catch up, so when they know the component for

the area I'm working on they would become more creative in what they work on at home, so they become real partners."

Hana (551-561)

For this therapist, to achieve "real" partnership in EI the parents need to: 1) set the intervention goals collaboratively with the therapist, 2) monitor the progress of the intervention, and 3) follow up at home. The therapist concluded her description with a rather pessimistic view:

"but this whole thing is something to dream of, this level of cooperation, it is just not possible now in Jordan"

Hana (564-566)

For this therapist, this level of collaboration requires awareness of what EI is and what the parent role should be even before starting the intervention, her perspective of focusing on the awareness of the community as the way to achieve "ideal" EI justifies why she finds this feat *"something to dream of"*:

"awareness should be on all levels, like for the doctor, the community, those centres for motherhood and child care, they should have posters and pictures about EI, like anything to invite the parents and make them know there are such programmes"

Hana (584-588)

This view of the importance of awareness to the parent role within EI is shared by another therapist:

"so in fact our work is not just doing therapy's sessions, we have to do awareness sessions for the parents and even more awareness until they are with you on the same path then you can do the therapy for the child"

Reem (541-550)

Her view of her role as a therapist focuses on raising the awareness of the parents concerning their choice of intervention goals, however for this therapist she perceives the "Ideal" EI as one being implemented by the therapist but based on the parents' awareness:

"there should be a role for the parents you know, like what do you as a parent want for your child? and what do you expect from your child. and if the parents are unrealistic about their priorities we as therapists can take them back you know like what you are asking for that is too much, let's think realistically!

Reem (542-546)

In a way this therapist combines the collaborative role of parents; in setting intervention goals; with the "expert" role of the therapist in guiding this choice and prompting "realistic" goals.

Another therapist anticipates difficulty in achieving an "ideal" EI in Jordan, however this therapist attributes this difficulty to the cultural construct within the community, which relies heavily on the "expert" status of the medical professionals:

"now based on our background here in Jordan, that (I am the therapist) I don't know if this fits with such role, that as a therapist I'm not the one in charge, I'm just here to help and support."

Lina (155-158)

This view towards the cultural impact on achieving productive collaboration with parents was shared by another therapist, who confirmed that this level of collaboration is still not possible in Jordan:

"we are not yet in this level [partnership], we try our best to explain to the parents that this is the best way to do the therapy; that they need to become active partners, and the way to explain this is by listening to what the parents need to say and so they would in turn listen to us"

Amal (129-133)

Reflection: *I wasn't happy with this interview and felt that I should have tried to schedule it in another time, because the therapist had a very busy schedule, but this was the only possible time for her to do the interview. I felt pressured into keeping my questions brief and trying to at least get her views in as much details as possible. She also seemed to be worried about her answers, she was one of my students while I taught at the university and she had been working for less than a year, I think she was treating me like her teacher and answered very carefully as if she was in a test. I feel I have conducted this interview in the wrong circumstances and my role as researcher was confused with my previous role as teacher.*

For this therapist, the reason it seems difficult to achieve partnership with the parents relates again to the knowledge and awareness of what OT can offer, at the same time she finds parents struggle to understand their children's problems:

"the problem is that our profession is not clear, people do not understand what we do, and also they don't understand what is the problem with their children it is still unclear in many cases"

Amal (138-142)

The role of cultural understanding of the partnership between the therapist and the parent was also mentioned by another therapist, she explained the difficulty in understanding partnership when this concept within a medical situation is unclear in the Jordanian culture:

"maybe because there is no awareness in our community about what being a partner is, so it is difficult to get people to understand this role, so I think for now at least asking them to be trainees is better. I wish we could reach the point when the parents would be real partners in the therapy! it would be great!"

Bayan (268-274)

In a way both therapists agree on the complexity of achieving a productive partnership with the parents, when such partnership relies on dismissing the higher status of the therapist, and promotes an active role of the parents. Both criteria in their perspectives do not fit with the cultural understanding of the role of a medical professional and the patient.

Another possible reason is described by this therapist:

"there is also another cultural reason, in some case the parents do not accept the child so the grandparents or relatives they start caring for this

child, so here you will deal with an older generation, people who are still following older ideas, this will influence whether they would know of these kind of programmes, or if they could take the child to such centres, or if they could be partners in the intervention"

Hana (344-351)

Here the therapist describes a common situation related to the Jordanian culture (or Eastern Muslim cultures in general), where the extended family supports the parents of a child with disabilities by taking on a care giver's role, thus the EI team will be dealing with a grandparent or an uncle or aunt of the child. In the example the grandparents would take over the responsibilities of attending sessions at the EI, in which case the team will be dealing with people from an older generation who still have expectations coinciding with the medical model, or adhering to the higher expert status.

4.3.3.1. Communicating the role of OT to the parents:

One of the challenges the therapists described when discussing parent-therapist collaboration was the difficulty in explaining their profession, one therapist clarified that the majority do not know what occupational therapy is when they start the EI programme:

"the majority do not [know about OT]*, I mean it has improved compared to when I started work 14 years ago, there is a huge difference in the understanding of OT from the clients"*

Lina (236-239)

Another therapist attributed the parents' limited knowledge of occupational therapy to the profession being unclear; however she did not explain why:

"the problem is that our profession is not clear, people do not understand what we do, and also they don't understand what is the problem with their children it is still unclear in many cases"

Amal (138-141)

On the other hand, another therapist was specific in describing the struggle she faces in communicating with her clients, referring to the language used in her OT education and the language she must use with the parents:

"I need to translate the terms to Arabic because we learned in English, I use Google to translate, like the term grasp or release, reach and so on, it is a problem because these terms are used a lot in the session but I know them in English"

Bayan (310-315)

Although not stated clearly by any therapist, the difficulty that the three refer to could be a combination of limited awareness about occupational therapy in the Jordanian community, a complex profession to explain to the lay person, and the fact that therapists learn about occupational therapy in English while they and their clients' first language is Arabic. However; it is clear that communication with the parents is impacted by the language used by the therapists, be it English or translated Arabic. In fact, one of the therapists explained her strategy to help

parents in the sessions to include using simple Arabic words while training the parent:

"I tell her [the parent] *while I show her, I use Arabic terms as much as I could to help her understand why I'm doing this, and the next time she does the exercise and I give her comments so she could do it at home"*

Bayan (293-297)

4.4. The power imbalance theme:

To conclude this chapter I will present the main theme the power imbalance again; however, the findings from phase one and two will be added to complete the picture of the power dynamic within parent-therapist collaboration. The analysis process led to the generation of this theme by combining the findings from phase one and two and reflecting their impact on the parent-therapist collaboration, this analysis process is presented in Appendix 16 The power imbalance theme development from findings. In the following Figure 9: The power imbalance theme - combining phase one and two findings I will attempt to locate the different themes from this study as elements, results, or influencers on the power dynamic within the collaboration.

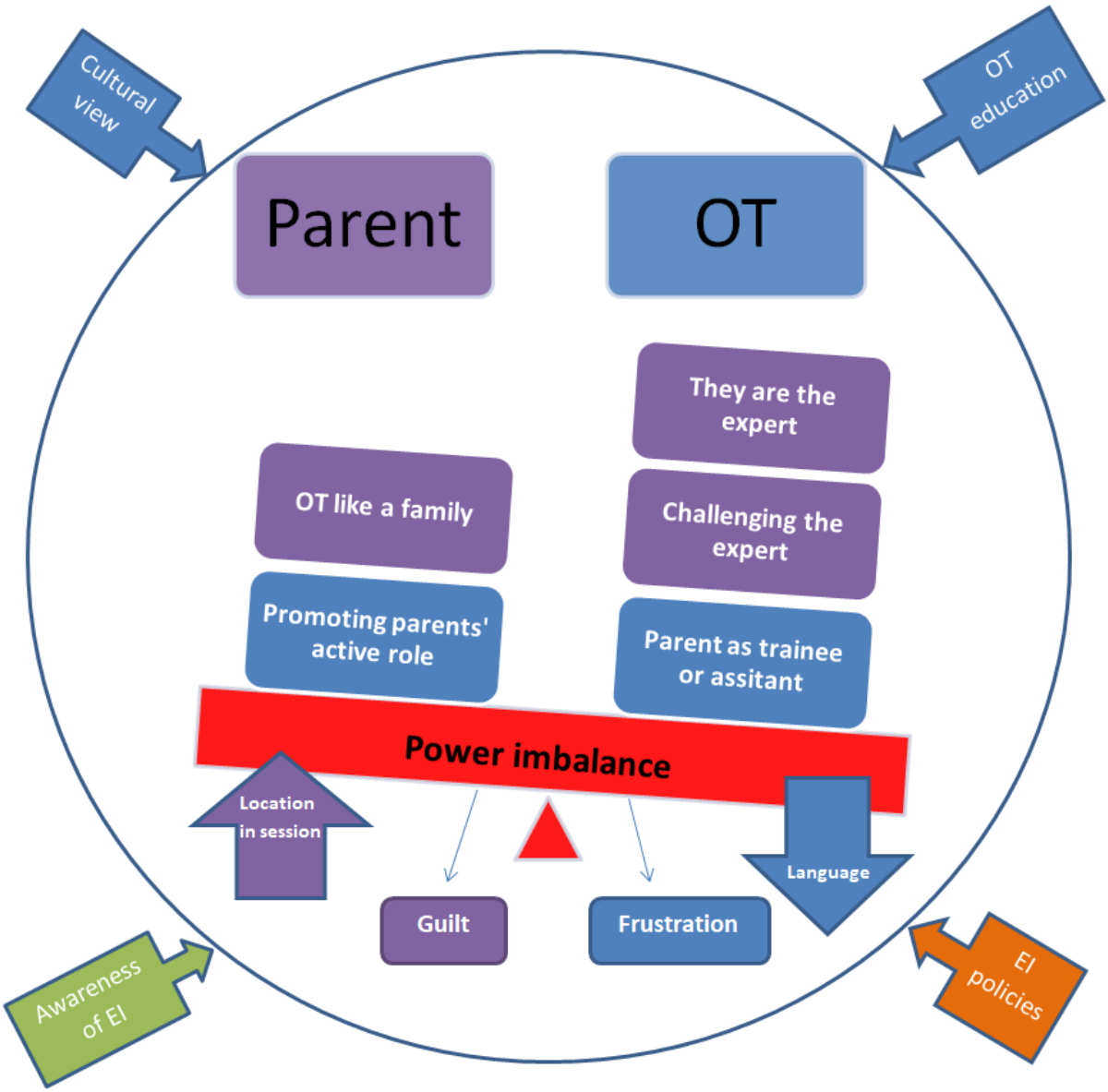


Figure 9: The power imbalance theme - combining phase one and two findings

4.4.1. **Elements of the power dynamic:**

The parents discussed their perception of their role within EI and how they viewed the therapists in the parent-therapist collaboration, this is represented in purple on the left side of the power imbalance scale. While the therapists discussed the strategies they used to promote an active role of the parents, as well as how they

categorise parents, this is represented in blue on the right side of the power imbalance scale.

The 1st phase of the study which included observations and record reviews also resulted in descriptions of the power imbalance; the parents' location within the sessions, and the language used by the therapists. I have used the colours purple or blue to indicate whose location or language this is related to. These two elements contribute further to the power imbalance.

4.4.2. **Influencers on the power dynamic:**

The power imbalance scale is surrounded by a circle which indicates an external influence on the dynamic; this is represented by four arrows including: Cultural view, OT education, Awareness of EI, and Early intervention policies all of which were discussed by the therapists under the theme (Early intervention within the Jordanian culture).

4.4.3. **Results of the power dynamic:**

In the interviews with the parents and during the observations within the 1st phase of this study parents expressed feeling guilty about their role within the early intervention, this guilt was linked to the parents' inability to meet the demands of the therapists, and their limited involvement due to their work and family responsibilities.

On the other hand therapists made expressions of frustration towards their perceived role, and the lack of awareness from parents or the community

regarding occupational therapy. This frustration was evident when therapists discussed the responses of parents to their work.

When the power dynamic elements, results, and influencers are all combined we can see an overall picture of the reality of parent-therapist collaboration, which was studied in this research.

The following chapter will discuss the resulting theoretical framework which was constructed to explain the development of parents-therapist collaboration in early intervention.

5. Chapter Five: The resulting theoretical framework The (Power scale)

5.1. Introduction:

This chapter will focus on the third aim of this study: Generate a theory to describe parent-therapist collaboration within early intervention in Jordan. I have developed a theoretical framework based on the findings discussed in the previous two chapters (Data analysis and findings phase1, and Findings phase 2). Using the main theme the (power imbalance) which describes the parent-therapist collaboration within the early intervention programme in Jordan, I have developed a framework to illustrate the elements of the parent-therapist collaboration, and how power dynamic within this collaboration could shift from one side to another. The resulting theoretical framework is represented visually in Figure 11: The power scale theoretical framework.

Following the description of this framework and the different elements within it, the power scale framework will then be deconstructed into different possible scenarios, each describing the relationship between the elements in either a positive or negative situation. To achieve this I will be using a simplified diagram that details how each element could be represented. There are two main possible scenarios discussed and each will result in a visual representation of the power scale highlighting the power dynamics between parent and therapist. The final

section of this chapter will present chosen examples from the findings of this study to illustrate and test the use of the power scale framework with actual data.

5.1.1. From data to theoretical framework, the analysis process illustrated with an example:

To illustrate the analysis process in all its steps I will be presenting here one example taken from one of the interviews with Occupational therapists. In this example I will begin with the words of the participant in English translation, followed by the codes derived from one specific quote, and illustrate how this code developed into category then subtheme. Finally this subtheme will be linked to the main theme in the findings which is the Power imbalance theme, and later linked to the elements of the theoretical framework power scale. Appendix 11 presents the page from the transcripts with the written codes and reflections.

1) Translation and reading transcripts:

The occupational therapist Bayan (pseudonym) who at the time of the interview worked in an Early intervention programme was interviewed in Arabic. Her interview was translated into English as the first step of analysis. In this translation I used my background as an occupational therapist from Jordan to translate literally and find the equivalent words when needed. This translation process was used as a way to acquaint myself with the transcript, which is recommended in constructivist grounded theory analysis as an essential step, emphasising the role of language in capturing the meanings which often relies on the interpretation of the researcher, utilising sensitising concepts as starting points to initiate analysis (Charmaz 2014).

The translation process provided an opportunity to examine terms used by the participants, then reflecting on my own interpretation of these concepts. Earlier in chapter three (page 89) I have used one specific example from an interview with another therapist to illustrate the impact of translation as the first step in analysis.

2) Coding and categorising codes:

The following quote will be used as an example to clarify coding and categorising of codes used in the analysis process:

"M: I find parents would want to know about OT, you know what we do, what does OT mean, how can I help the child, most parents ask this, so I explain to them, you see I have to give them examples and sometimes even set the goals myself, but when we start talking and they realise what I focus on I find they start to give some goals of their own, like (yes my child can't hold the milk bottle) so they start to give me the difficulties they face at home, and that is great, so I keep asking them to give me their comments and then explain that those kind of difficulties will be the base for our goals"

Bayan 213-226

Using Gerunds to form codes as advised by Charmaz (2014) I have derived the following codes and colour coded them to correspond to the relevant words:

- Explaining what OT is for new parents
- Giving examples of goals to parents
- Setting goals with the parent
- Asking parents for information on difficulties they face at home

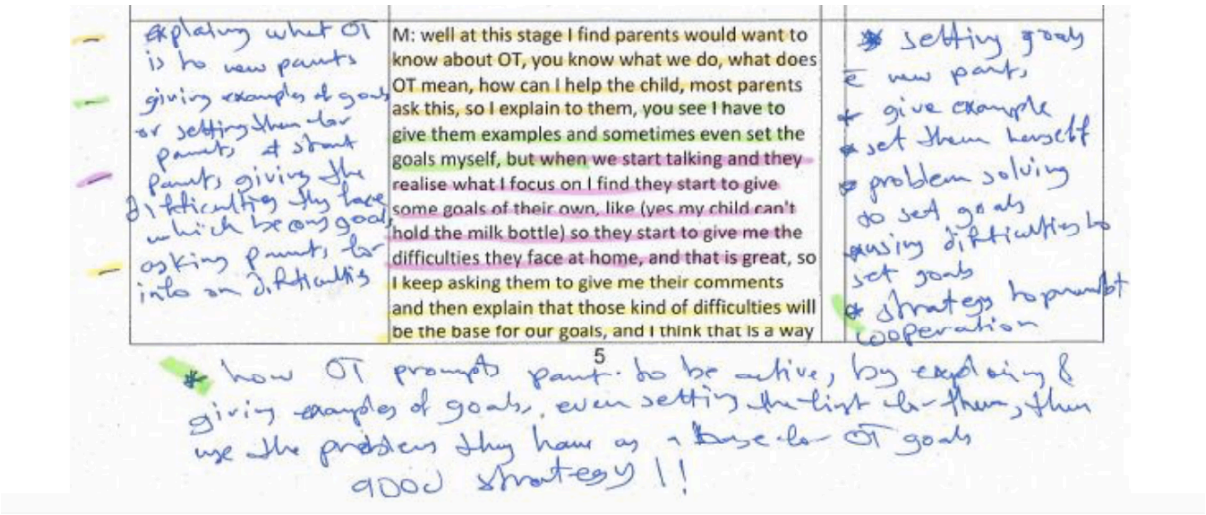
In the transcripts I did the coding manually, by writing the codes on the right side of the transcript to explain in brief what the participant is saying, thus relaying their

thoughts in short and sequencing those ideas to provide an understanding of the perspective of the participant. I used line by line coding to focus on the meaning behind the words rather than the exact meaning of each word, especially since this is translated from Arabic. However when one word seemed to relay a specific idea on its own it was coded alone, and this was particularly seen when participants were using professional language or a metaphor.

Each interview yielded many codes, which then were grouped under categories and placed on the left side of the transcript, for this example the categories are:

- Problem solving to set goals
- Strategies to prompt parent cooperation in goal setting
- Using difficulties parents face to set goals

When writing the category I tried to use nouns instead of verbs to help me in forming a family of codes under which I grouped several codes from the same interview, then moved to compare categories between interviews from the same participant group (parents or therapists). In this way I looked for codes that discussed the same topic or idea, then considered agreement between the codes to group similar ideas. When there was a contradicting idea I used a different category for it so that disagreeing opinions are also presented in the categories. Appendix 11 shows the analysis steps of coding and forming categories in one interview, I used colours to form a visual guide for the analysis.



An Extract from Appendix 11

3) Forming subthemes and themes:

The next step in the analysis was to list all the categories in one table then group them under larger categories, this formed the foundation for subthemes and later themes. The process of forming themes relied on reading all codes and understanding their meanings, then using categories that will represent the meaning in general to form one theme. It was a long process that required going over the codes and categories several times and using different methods for representation to ensure the essence of what the participants said was not lost. At the same time comparison among categories within interviews helped form larger categories and to find similarities and discrepancies between views.

For this example: the category (Strategies to prompt parent cooperation in goal setting) evolving from the codes was merged with other categories from other interviews such as (Prompt parent involvement, Problem solving to set goals, and active parent role) to produce the subtheme (Promoting parents' active role). This became one element which is evident by the therapists in their efforts to balance

power in the parent-therapist collaboration, thus highlighting the efforts discussed by therapists to help parents assume an active role in the EI.

4) Building the theme (power imbalance) using analysis memos and reflection notes:

The process of the analysis included memo writing, this was added to the top or bottom of each transcript page, and typically the analysis memos helped in describing the view of the participant which later formed the basis of the categories. For this example I wrote one analysis memo:

> "how OT prompts parents to be active at the start of EI, by explaining and giving examples of goals, setting goals at first for them, then use problems they have explained as a base for OT goals"

This description of the how the therapist prompts active parent role in EI was later used to explain the subtheme (Promoting parents' active role) which included categories focusing on strategies used by therapists such as helping parents set goals, explaining goals and giving examples, and using problems explained by parents to plan an intervention. This subtheme described how therapists attempted to help parents move from a passive role where they received goals set by the therapists, to being active participants in the planning of the intervention. The subtheme (Promoting parents' active role) was then related to the therapists' role within parent-therapist collaboration, and thus, when building the theme (the power imbalance) I marked this subtheme in blue to indicate it was generated from interviews with the OT, however it was placed under the column of parents because it is an effort made to balance the power in this relationship. Thus while it

was made by the therapists it still is an action that aims to increase parents' role in EI and give them more power in this dynamic.

5) Reflections within the analysis process:

Reflections were documented on the transcripts at the top or bottom of the page. These were mainly reflections during the analysis where I related some code to my own practice, or found a comment which elicited an emotional response which I needed to write down to become aware of its impact on the analysis process. For this specific transcript I had documented one reflection (seen in Appendix 11):

Reflection: OT point of view at the start of the OT-Parent rapport, if they have no time to build a foundation for the collaboration, how can they encourage parents to be more active?

This reflection showed some of my own frustration with the EI system which did not allow time for parent-therapist collaboration to be established. I was aware this is my own frustration, which I sensed from the description of the therapist, however I was also aware that the participants did not voice this frustration as clearly, so I was careful to limit my description of the participant's frustration to what they did say, not project my own feelings.

6) Building the theoretical framework (Power scale):

The second level of analysis focused on elevating subthemes to become concepts that will constitute a theory. In this case the subtheme (Promoting parents' active role) was viewed as part of the elements of the theoretical framework (the power scale). To achieve this I returned to the significance of this subtheme, and

considered why therapists described their efforts to promote parents' active role. I also reviewed the different categories under this subtheme to understand how therapists achieved this goal. My analysis of this subtheme revolved around the reasons why and the how of this action, this is described by Charmaz (2014) as a way to move themes from descriptions of views to a full formed theoretical concept. While this step is complicated and is impacted by my own understandings and views, it is essential in the constructivist grounded theory analysis process to move descriptive views into in-depth ideas that can be used to produce a theory. I used my reflections throughout the analysis process at this stage to reduce my own impact, and to help in focusing on the data and results rather than my own views. The process of using reflections was present in every step of the data collection and analysis, for example; in the transcripts I added reflections while I was generating codes, these reflections were placed on the pages of the transcript to link them with the words of the participant that elicited such reflection. When I moved to forming categories I read the transcripts and codes and used reflections to re-acquaint myself with the coding process and my thoughts at the time.

The subtheme (Promoting parents' active role) was linked to two explanations:

1. Support parent needs through knowledge
2. Empowerment/ encouragement using therapeutic use of self

Supporting parents became the "why" of the action therapists did to promote parents' active role - they used knowledge to support parents. At the same time the term 'therapeutic use of self' was used here to indicate the strategies

therapists used to help parents assume their role, these strategies were the “how” of promoting parents’ active role.

When forming the theoretical framework (power scale) both knowledge and empowerment were highlighted, and both were used by therapists to help parents assume more power in the collaboration, and so knowledge was formed from this subtheme and other themes as a theoretical element of this framework, while empowerment revolved to become the element of engagement.

5.2. Constructing the theoretical framework:

Charmaz (2006) describes the final stage in data analysis as a focus on the process of scaling up the resulting categories into theoretical concepts, while clarifying the connections between these theoretical concepts to achieve an abstract representation of the findings, and conclude with the theory or theoretical framework as a final result.

The findings of this research were discussed in chapters 3 and 4, and the main resulting theme (power imbalance) was represented using the following figure:

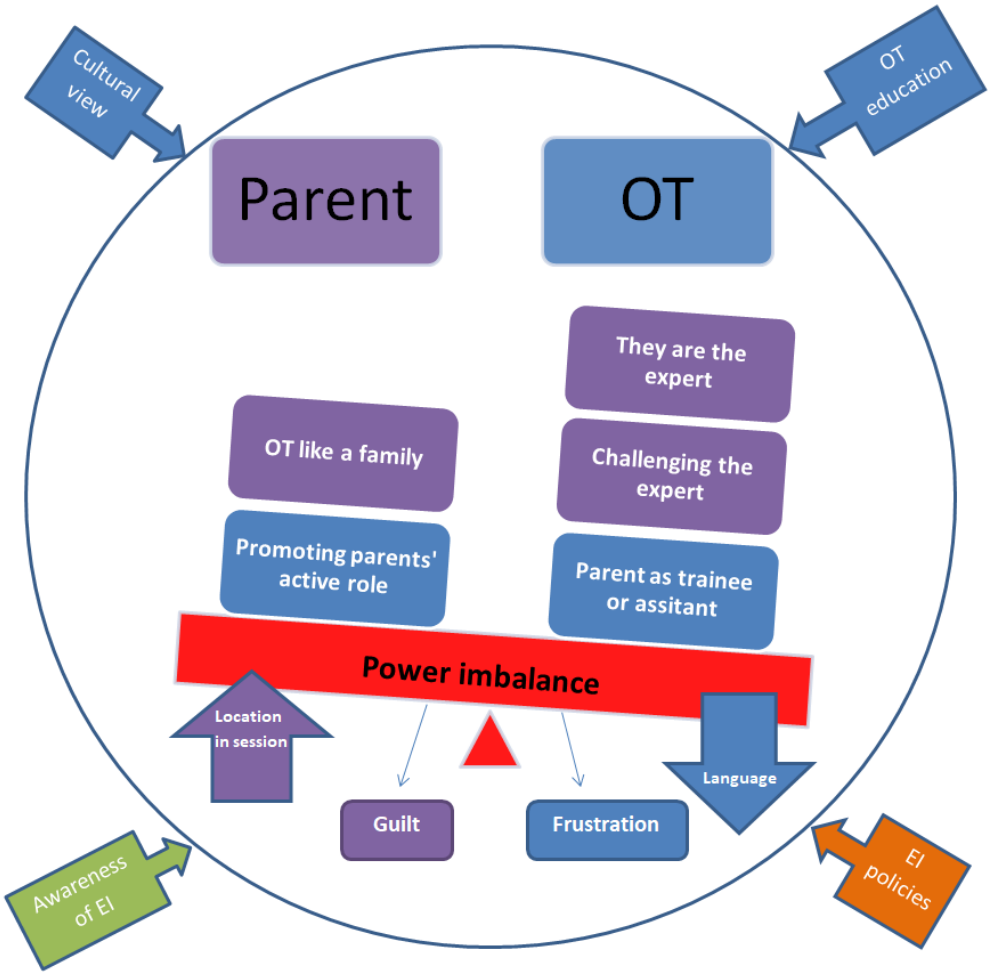
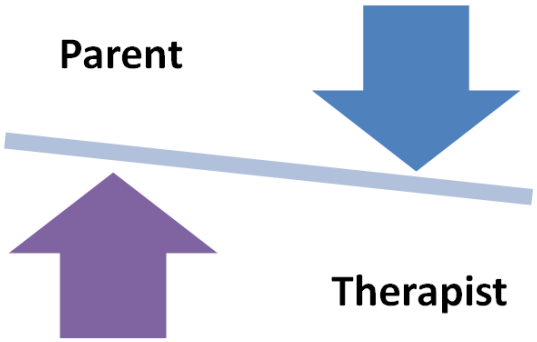


Figure 10: The power imbalance theme - combining phase one and two findings

In this theme (power imbalance) we can see a representation of the parent-therapist collaboration, where the relationship is seen as a scale that symbolises the power dynamics within the therapeutic relationship. The above figure 10 shows a clear imbalance between the power held by the occupational therapist in this collaboration, and the power that the parent possess. We can also see different elements (subthemes) to explain what contributes to this power imbalance, some of these elements are relevant to the parent such as “they are the expert” or the

therapist such as ‘promoting parents’ active role’, and others are externally influencing this collaboration such as cultural view and EI policies.

The evident power imbalance is an essential element in this collaboration, as in most relationships there is power dynamics between the two involved parties, one that shifts towards the party who has more influence or authority, and in **diagram 10 above** this power is clearly shifting towards the therapist in this therapeutic relationship. This power dynamics can be represented in a simplified scale as follows:



To understand the power dynamics we need to look closely at this scale and try to examine the elements that construct it. These elements are based on the different subthemes resulting from this research, such as “they are the experts”, challenging the therapist, parent location in sessions and Language use. However; these subthemes need to be scaled up into theoretical concepts to provide an abstract level of representation, and to do so the nature of these subthemes is analysed and then grouped under three main concepts: Knowledge, Expectation, and Engagement. The process of generating these concepts from the subthemes is demonstrated through (Appendix 17 The theoretical framework elements

generated from themes), where I have described the links between these subthemes, then derived the representing concept which reflects them. Then each concept is assigned to both parent and therapist with an explanation of its impact on the power dynamics, as well as how the three concepts are influenced by each other. This is represented with the following Figure 11: The power scale theoretical framework.

5.3. The theoretical framework (Power Scale):

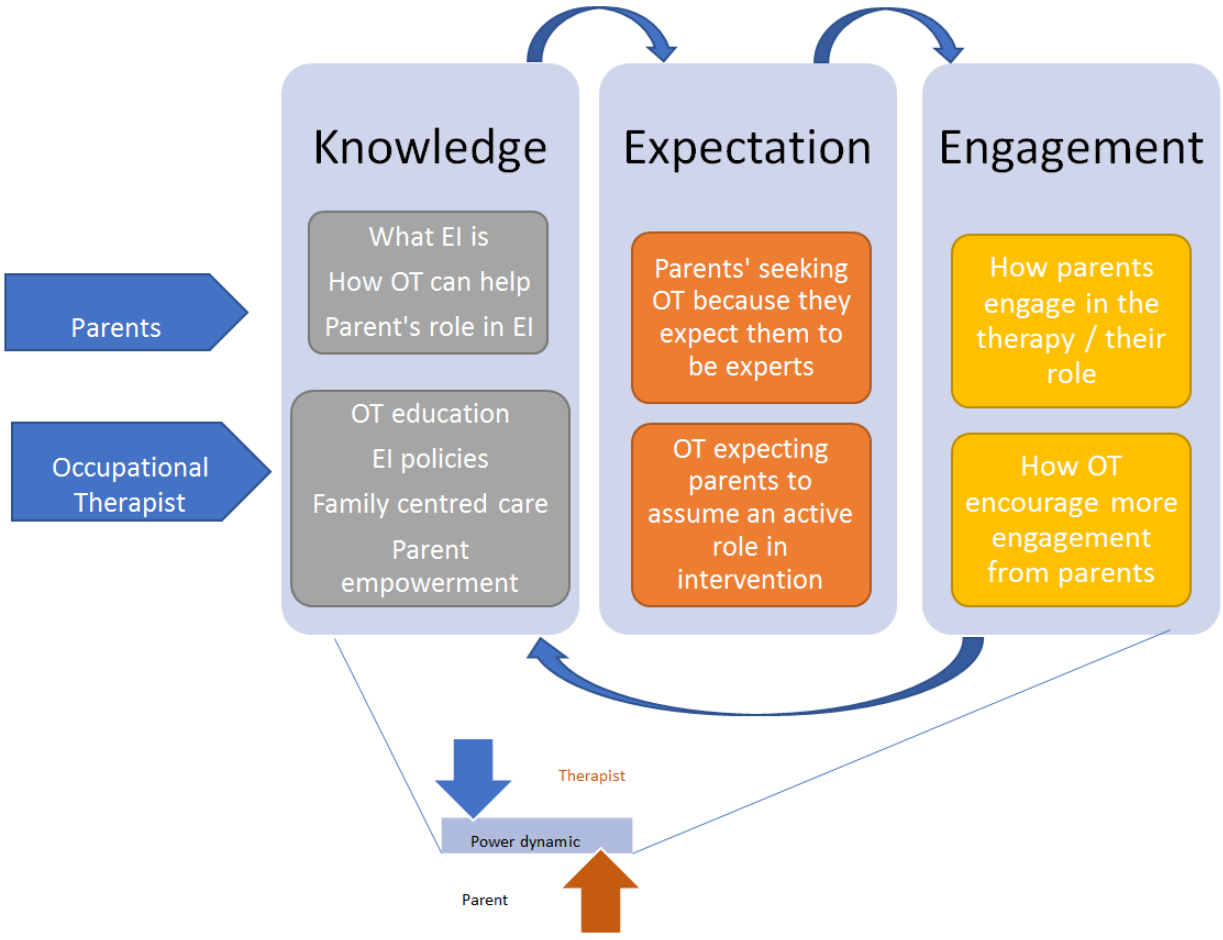


Figure 11: The power scale theoretical framework

In this framework the power dynamic between the parent and the therapist is represented with a scale, which is influenced to a balanced or imbalanced state by

different factors relating to the parents and the therapist. These factors are represented in the magnified section of the power scale which shows the elements of the power relationship: Knowledge, Expectation, and Engagement. For each element of the power relationship the parent or the therapist would have their specific factors which may increase or decrease their knowledge, expectations, and/or engagement. It is essential to define these main elements here: Knowledge, Expectation, and Engagement as they are represented here as theoretical concepts which have a specific meaning relevant to parents and therapists, as well as the early intervention context.

5.3.1. Theoretical concepts within the power scale framework:

Knowledge is defined here as the collected information which the parents or therapists have gathered regarding early intervention, occupational therapy, family centred practice, and the medical situation of the child, it also most importantly refers to the parents' knowledge of their child which makes them experts in their child. These information are obtained from different sources depending on the parent or therapist access to various knowledge sources, including technical education, health related publications, word of mouth from professionals or other parents, or the internet. With the parent-therapist collaboration seen as a process, there is a distinction between (initial knowledge) which the parent/therapist has at the start of the intervention, and the (accumulated knowledge) they will gather throughout the different stages of the collaboration.

Expectation refers here to the image the parent or the therapist would have built in their minds regarding the early intervention, their role within it, the anticipated progress of the child, and the collaboration. This image will reflect their perception of how the intervention should go, it is based on their knowledge but also their hopes and wants from the early intervention, as well as how their role and that of the therapists is viewed within their culture. While knowledge has the most direct influence on expectations in this framework, other factors might influence it such as the personal view the person might have regarding life, whether they are optimistic or pessimistic, or their general emotional status. Similar to knowledge, parents and therapists will begin the intervention with (initial expectations) which might be reinforced or changed as they develop their collaboration, and they form a (shared expectation) as their knowledge changes.

Engagement is the nature of participation the parent or therapist has in every step of the intervention, this participation is seen at three levels: 1) planning and decision making, 2) conducting sessions or therapy at home, and 3) empowerment. At each level the parent or therapist take on a role that is defined according to their collaboration with each other, this will be described within the framework to reflect how the engagement is seen. And this engagement will evolve from the start of the collaboration based on the expectations and knowledge, with possible changes happening depending on how the parent-therapist collaboration is developing.

5.3.2. **Connections between theoretical concepts:**

There is a link between these three elements represented with arrows in the power scale framework, describing how knowledge would inform expectations and then these expectations will influence the engagement. At the same time, engagement in the EI will result in gaining more knowledge of what the parent role is and what the programme could provide them, this will develop new expectations that might change the parent's engagement further either in its level or nature. The same links apply to the therapist; as their knowledge would form their expectations from the collaboration, and thus their engagement with the parents would be impacted to take an instructive or leading nature. And as the therapist engage further into their role as coach or hands-on therapist they will develop more knowledge that will change their expectations and in turn their engagement.

The process described above will have an impact on the power scale; as the engagement of parent and therapist move toward an active and supportive dynamic, the scale would balance showing a partnership between the parent and the therapist where they are both engaged actively in the intervention, and thus both have an equal role within their collaboration. However, when limited knowledge results in expectations of a limited role in the intervention from the part of parents, and a hands-on engagement from the therapist, the power scale shifts towards the therapist, placing more decision making and authority in terms of the intervention on the therapist, a status that makes the therapist the "expert" in this collaboration and the parent the "recipient" of a service.

The following diagrams describe two possible scenarios for this power scale:

5.3.3. **The supportive collaboration:**

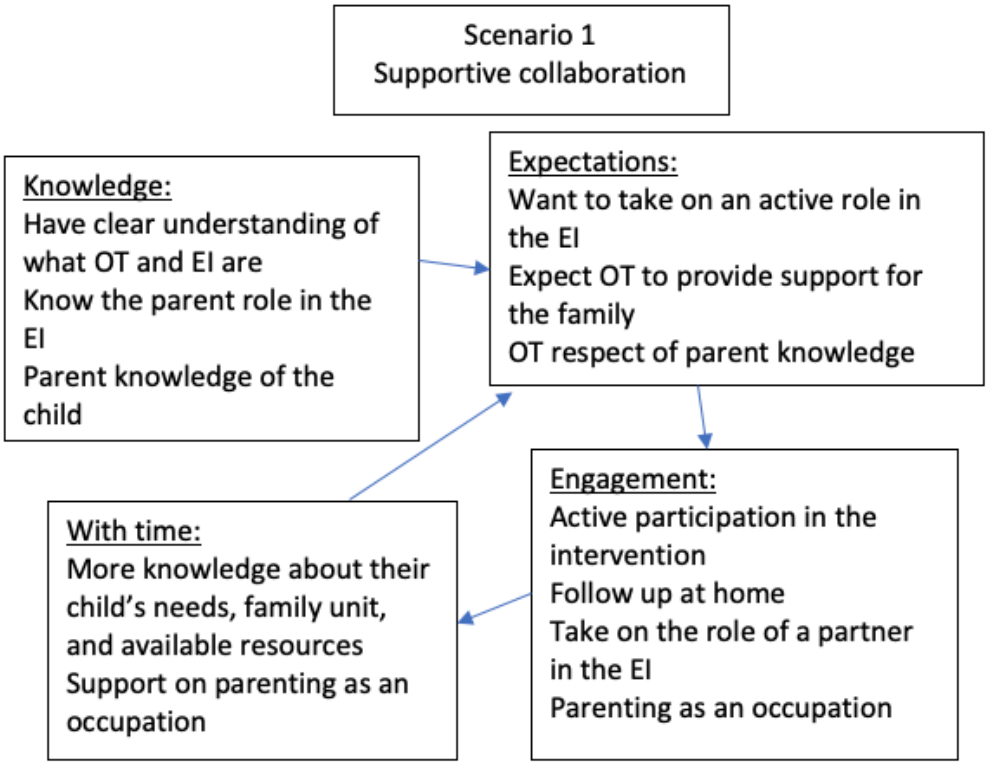


Figure 12: The supportive collaboration scenario - Parent perspective

In this Figure 12: The supportive collaboration scenario - Parent perspective, the parents are the experts in their child, they have accumulated knowledge of their family and child's needs, they also have had an opportunity to develop sufficient knowledge of what the early intervention programme can provide them, and the role of occupational therapy within this programme. This knowledge could be developed through contact with health professionals, or as part of the referral process when their child was first identified to need EI services. The parents also have some information on their role within the programme.

This knowledge will help the parent form realistic expectations from the EI and the OT, so they would expect to have an active role in the EI programme, and

anticipate support from the therapist while they are going through the different steps within the EI programme.

The result of these expectations would be an active engagement in the intervention, and possibly follow up at home based on the EI plan focusing on the family as a unit and addressing parenting as an occupation. This level of engagement can be described as a partnership with the EI team, in which the power dynamic places parent and therapists on equal footing. As the intervention progresses this partnership will provide the parent with support including more information on the EI, and detailed knowledge of their child's situation. This advanced knowledge will in turn help parents form realistic expectations from the available services for their child, which will continue to reflect positively on their engagement even after their child has made the transition to a school setting.

The power scale framework can also be used to explain how a positive collaboration could result from the occupational therapist's perspective. This is shown here in the following Figure 13: The supportive collaboration - the OT perspective:

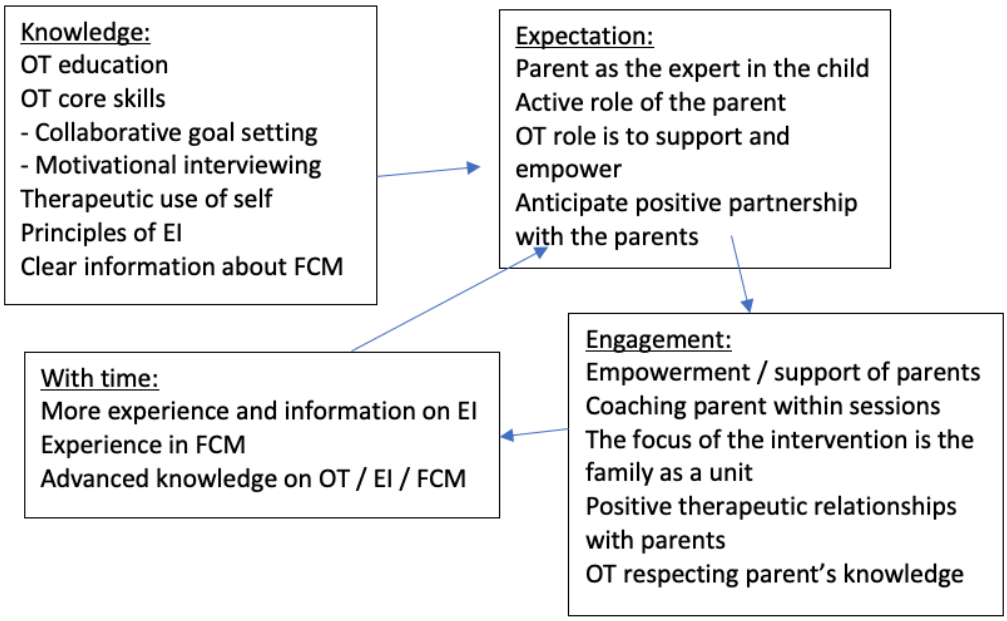


Figure 13: The supportive collaboration - the OT perspective

The start point is also the knowledge of the OT, this is gained though the therapist's professional education which if extensive would cover what early intervention programmes include, the role of the OT within these programmes, and the principles of family centred practice. Additionally, the OT education covers core skills that are essential for the building and maintaining a supportive collaboration with the parents, this includes but is not limited to: 1) collaborative goal setting, 2) motivational interviewing, 3) occupation based intervention, and 4) therapeutic use of self. Further knowledge could be gained by the therapist in the advanced area of early intervention through specialist placements or training.

With this knowledge base the OT forms clear expectations of what their role should be when starting collaboration with the parents, and the anticipated role of the parents within this collaboration. At the same time, knowledge of the family centred practice will help the therapist develop expectations related to the

expertise of the parents on their child, which is a foundational element of the family centred practice and the parent-therapist collaboration. This will form the expected partnership between the OT and the parent, which if based on clear understanding of family centred practice will be an anticipated positive partnership.

These expectations will lead to positive engagement from the OT, including using therapeutic strategies to empower the parents, support them with information and other required resources so the parents can take on their partner role in the intervention, and utilising core skills such as collaborative goal setting to form a positive partnership with the parents. The OT will engage in coaching the parents so they could have an active role in the sessions as well as at home using home programmes and visits, utilising the parents' knowledge of their child to formulate the EI plan with the parents so its focus can be on the family as a unit.

In this scenario with the parent and the therapist having enough information, positive expectations, and active engagement the result is a productive collaboration, one where the power dynamic takes on a balanced relationship placing parent and therapist with the same level of authority and influence on the EI programme. This is represented here with the following figure:

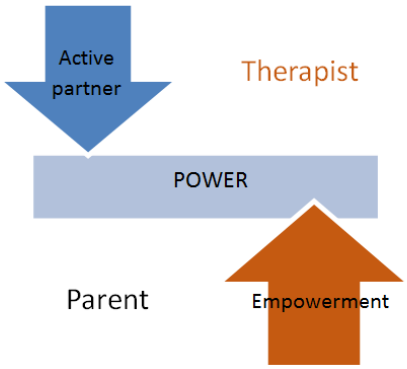


Figure 14: The power scale representing the Supportive collaboration scenario

The second possible scenario is related to how an uneven collaboration could form between the parent and the therapist.

5.3.4. The unsupportive collaboration:

For the parent:

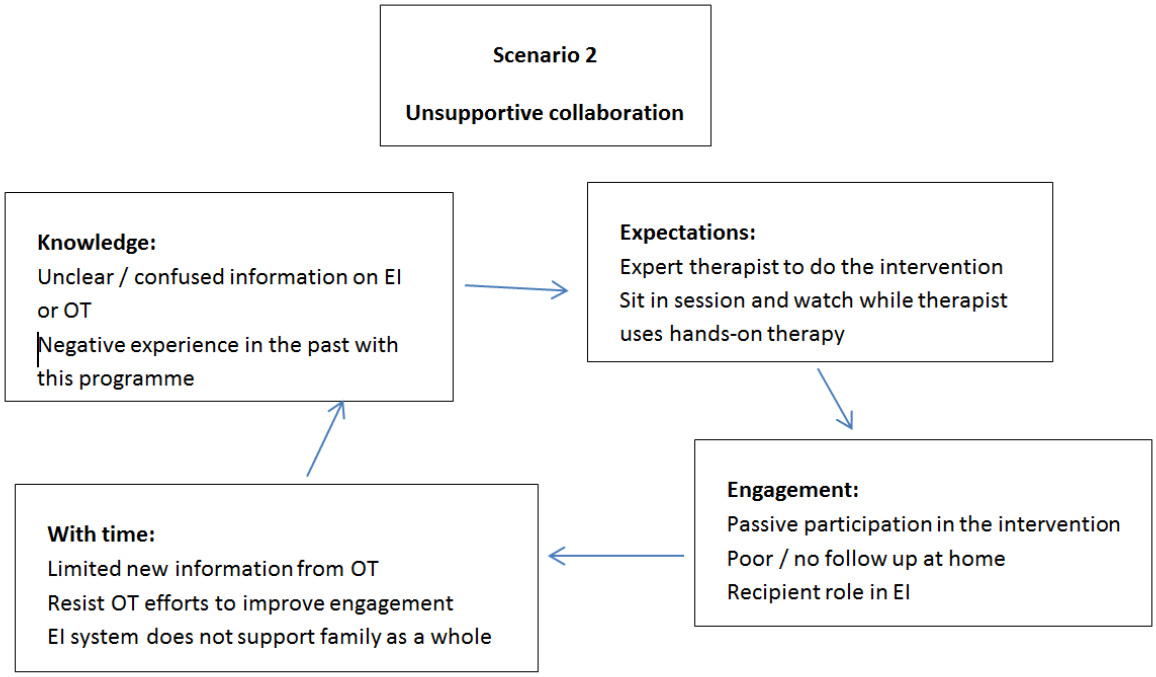


Figure 15: The unsupportive collaboration - the Parent perspective

At the start of the collaboration the parents have unclear or confused information on what the early intervention programme is. This information could be gained from the internet, other parents, or through the referral process which did not provide the parent with sufficient information. Some parents might start the EI programme after experiencing poor services which provides them with misconceptions or confused information about the role of occupational therapy or the EI programme in general.

The expectations resulting from this type of information would be reflective of this poor knowledge; with parents expecting the therapist to perform the sessions using a hands-on approach, and possibly give instructions to be followed at home. These expectations direct the level of the engagement of the parent in the intervention, they will be passive during sessions or meetings, leaving the therapist to make the decisions, and assume a recipient role in the programme.

As the EI programme progresses the knowledge of the parent could improve if information is provided, which might reflect positively on the engagement of the parent, however; in this diagram the EI staff do not support the parent with correct and thorough information, and so the expectations of the parent will continue the same and so is their engagement.

From the perspective of the therapist we can see possible influences on the collaboration as described in the following figure:

For the OT:

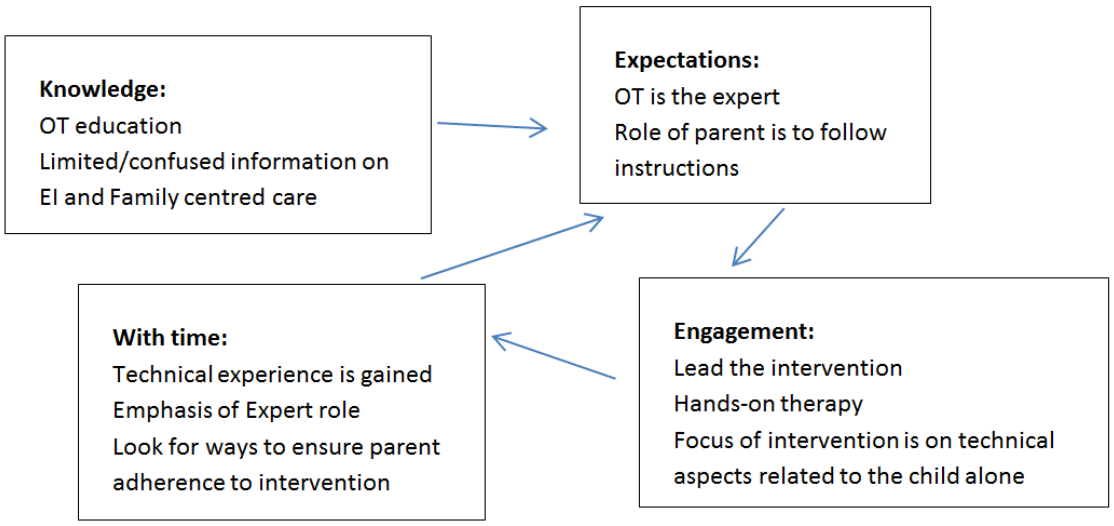


Figure 16: The unsupportive collaboration - the OT perspective

Here, the OT starts off with limited knowledge on their role within the EI, and confused information about family centred care. Their expectations revolve around the expert status of the therapist, they will anticipate being the professional in this collaboration who has the answers and is directing the intervention. The OT will expect the parents to take the instructions they offer and follow them at home. The OT will engage in the intervention as the leader, they will use a hands-on therapy within sessions, instruct the parent on what is best for the child, and focus the intervention to be child centred without considering the family as a whole. With time the therapist will gain technical experience relevant to child – centred therapy, their expert status will be reinforced with more technical knowledge. Moreover, unless the therapist utilises OT core skills such as collaborative goal setting, active listening, and motivational interviewing to address issues of ambivalence about change, or undertake advanced training to update their knowledge on family centred care, the therapist will continue to expect the parent

to adhere to their instructions and the cycle will not be broken. This will result in an unbalanced power dynamic, where the therapist will have more authority in the decision making, and maintain their expert status as represented in the following:

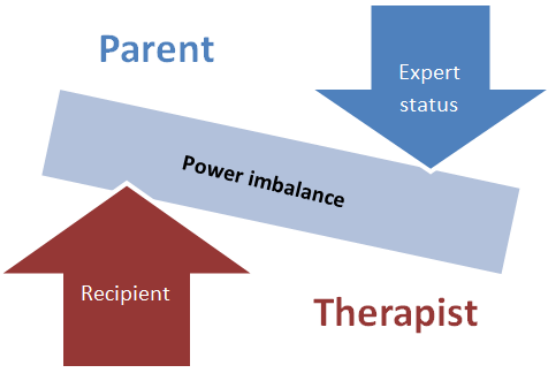


Figure 17: The power scale representing the unsupportive collaboration scenario

But for this scenario we can predict another possibility for the OT:

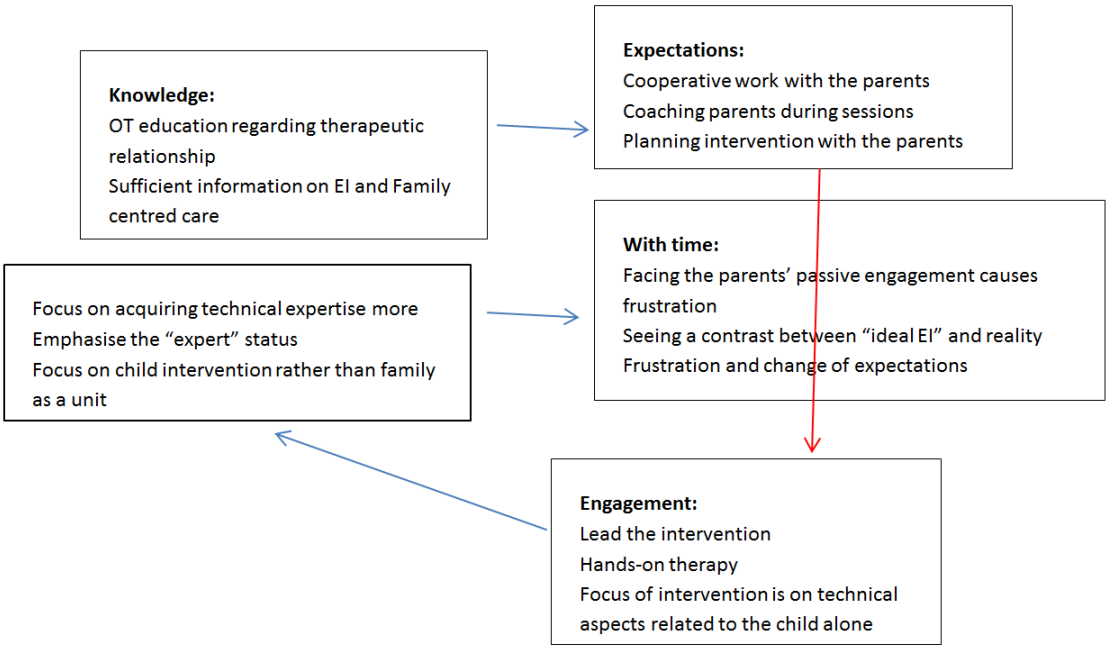


Figure 18: The unsupportive collaboration - another OT perspective

In this scenario the OT starts the intervention with strong knowledge and positive expectations, but they face passive engagement from the parents (as described in scenario 2 unsupportive collaboration). This resistance from parents will cause the OT frustration as they compare the reality and what they have learned about as the "ideal" EI. With time the OT might change their engagement and adopt a hands-on therapy, with them leading the intervention, they also would focus on technical aspects focused on the child rather than the family. This engagement will result in the OT acquiring more technical expertise but less empowerment skills, so they will move towards an expert status.

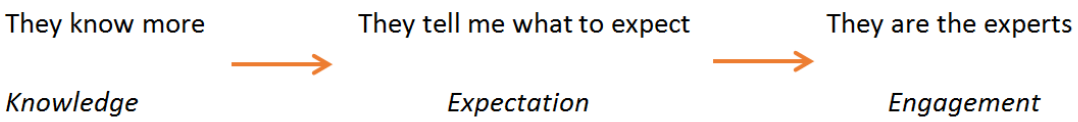
This specific situation is likely to occur with new OT graduates who are at the stage of using their knowledge and forming their perspective regarding their role, if the EI system does not provide them with advanced training and support from experienced OT they are likely to shift their role towards an "expert" role so they can meet the expectations of the parents. The work culture within the institution will also have an influence, as new graduates would adhere to the expectations of the institution whether it supports empowering the parents, or the clinic culture of expert authority is prevalent.

5.3.5. **Examples from research findings:**

In this section, I illustrate how the power scale operates in practice using four examples from the findings in my study:

5.3.5.1. Spoken like an expert:

When we look at the findings from this research (Chapter 3 and 4) we can identify where the three main elements of the power scale framework are present, as both parents and therapists described their own knowledge at the start of the EI, and what they perceived as the knowledge of the other party in this collaboration. One parent referred to the expert knowledge of the therapists as the reason she expects them to tell her what to do; describing her level of knowledge as less than that of the therapist ***"but I say she knows better than me, I wouldn't know more about therapy than the therapist"***. This perception of expert knowledge was linked to the expectations the parent has of their own role, as they await the therapist to tell them what their role is. A link that could be represented with the following:



The observations of parent-team meetings and assessment session discussed in Chapter 3 (in theme: Lost in translation) revealed how therapists used the English language when they discussed the child in front of the mother. They also were observed describing the child's problems using professional language that was not clear to the mother, although the mother requested an explanation for the terms used the therapists continued by the same unclear terms. These observations showcase the manner in which therapists were using their expert knowledge (professional language) to emphasise their status in front of the parent, which was an indirect way to formulate the expectations of the parents:

Professional language (English) = Expert knowledge

Expert Knowledge → Expert power within the parent-therapist collaboration

5.3.5.2. Who has better knowledge to set the intervention goals:

This emphasis of expert knowledge was again revealed in the interviews with the therapists, where the therapists discussed how they dealt with parents who had priorities for the intervention which did not match those of the therapist. One therapist described her strategy using the word (نسایر Nesayer) which translates as (placate or appease) to hint at how she went along with the parents' priorities until she convinced them to follow her own intervention goals, and how parents develop "blind trust" in the therapist with time.

"a good percentage do change, they even develop <u>blind trust</u> in the therapist so you could actually add any goals you want to the therapy and can convince them of it"

In this example the therapist places her own knowledge at a higher level than the parents. She describes how parents would need to change their expectations from the intervention to fit her own expectations, and to do so she works on convincing the parents of her expert knowledge, the strategy she describes is to humour the parents with the goals they set for the intervention while she actually focuses the intervention on the priorities she deem more important, "***I let them do as they please for now, and focus on her own goal, but based on the priorities that I have set you know, not randomly"***. When the parent sees the positive results in the intervention based on the therapist's goals the parent's expectations shift towards

"blind trust" which is explained by this therapist as her ability to *"add any goals [she] wants"*. The power dynamics can be illustrated by the following figure:

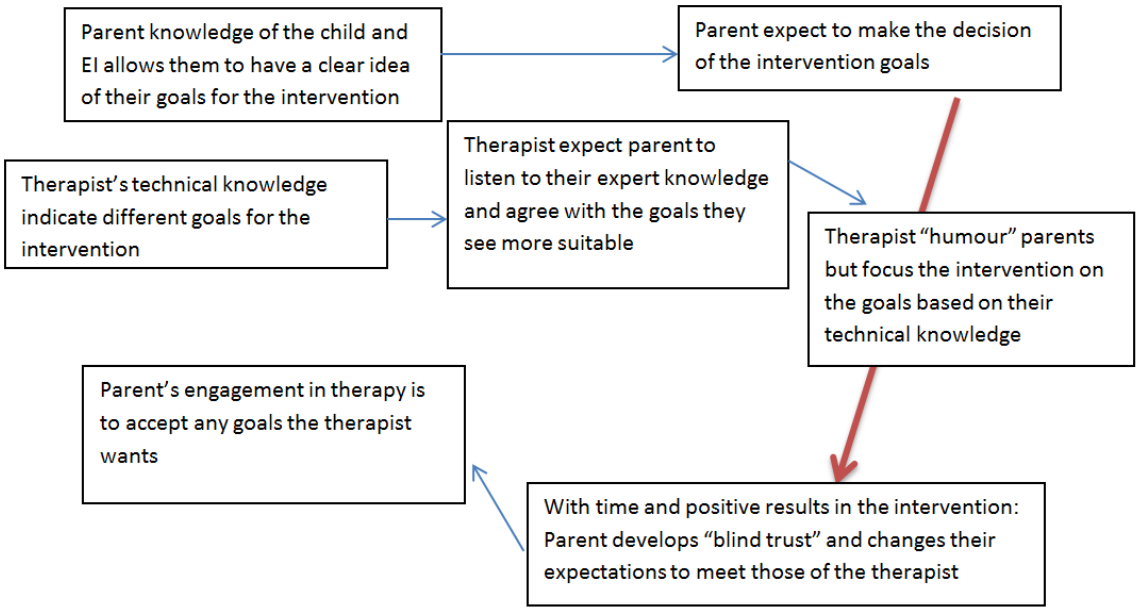


Figure 19: Example - Who has better knowledge to set the intervention goals

5.3.5.3. The weight of guilt:

In chapter 4 we discussed the guilt emotions that results from power imbalance in the parent-therapist collaboration. One parent used a metaphor to describe how the EI team blamed them for the unsatisfactory results of the intervention "***here they place this responsibility over the parents"***, which resulted in feeling guilty that the parents could have done more at home to achieve the intervention goals. The actual words of this parent in Arabic gave an image of the team placing the weight of responsibility on his shoulders (بيحطو المسؤولية على ظهر الاهل).

What is interesting in this case is the events that led to this final conclusion of guilt and exchanging blame. This parent described how they at the start of the EI programme set one goal for the intervention which was for their child to walk, the parent then described how the EI team tried to convince them to change this goal

because it was not reasonable, however; they maintained that had the team dedicated efforts on this priority, and had the parent worked more at home their child would have achieved this goal eventually.

To unpack this description we need to examine the parent and therapist knowledge, expectations, and engagement. This is represented here:

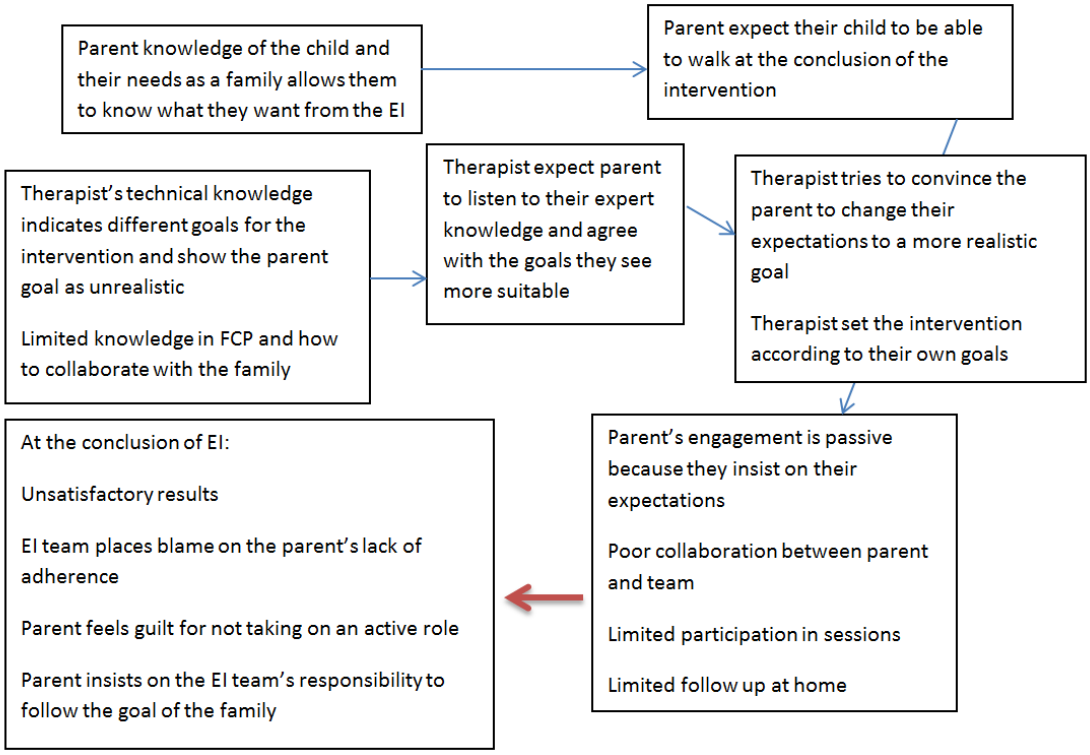
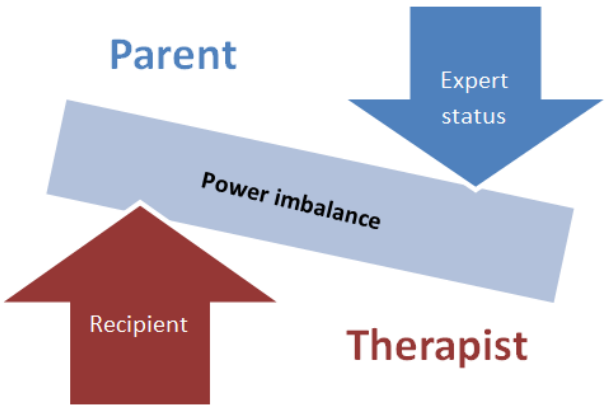


Figure 20: Example - The weight of guilt

This example shows how the power dynamics between parent and therapist could impact the success or failure of the EI intervention. This power dynamic is evident in the manner in which the EI team dealt with the parent throughout the programme; although the parent might have had unrealistic goals for the intervention but the EI team adopted an "expert" position by insisting on their own goals and expecting the parent to change, thus disempowering the parent and causing them to assume a passive role in the intervention.

The dilemma the EI team faced here was whether they should look after the interests of the child; by relying on their technical knowledge and insisting on the goals they deem suitable; or consider the family as a whole and reach a compromise with the parent to ensure their positive engagement in the intervention. This is a situation illustrating a different perspective of the parent, who linked their limited engagement in the intervention to their non-satisfaction with the goal set by the EI team. Thus, the parent assumed a passive role and did not follow up at home as they should have, resulting in the poor progress of their child over the period of the EI programme.

In the previous example (Who has better knowledge to set the intervention goals) the therapist used strategies to convince the parent with her expert goals and consequently her judgement. In the second example (The weight of guilt) the therapists were not successful in convincing the parents, but in both examples the therapist adopted an expert position, and in both examples the power dynamics shifted towards the therapist:



5.3.5.4. Conflict of power:

The final example to illustrate the use of the power scale framework to represent parent-therapist collaboration is narrated here by one parent in the research, the use of this parent's words is intentional as they reflect his emotional reaction as well as the sequence of events he faced:

"to be honest I had a suggestion regarding this [scheduling sessions], frankly there was a misunderstanding regarding my suggestion, like the staff thought I was interfering in their work, what I suggested was related to my situation, I asked them to fix our schedule for a whole year so I can fix my work schedule for a year accordingly and I wouldn't have to change the schedule every month! and I told them there are several parents like me. the staff refused the idea, so I went to the manager of the centre, the manager liked my suggestion and said this is very reasonable, but later I am surprised that the EI team took my suggestion as interfering in their work, and somehow stepping on their toes or something like that, so they took a defensive position and told me that I don't know their work and have no idea of their efforts, so I said this is merely a suggestion if you like it then apply it, if not it is ok, but they shouldn't be this stressed"

"I really did not like the way they handled this, the way they talked was not respectful"

"I would say that at the start I was a partner in the programme, but after this incident that I just described I became a recipient, because you know I felt they were even treating me different than other parents, like I'm speaking frankly here, if we are few minutes late they cancel the session, so it became a personal

issue, like I thought we are professionals, there shouldn't be personal involvement if I suggest something, so even treating me as parent is different, they would look for any mistake, and wouldn't let any issue pass, it was different than the way they treated me before, and different than how they treat other parents, so I changed my attitude, I would come here for the session only, just get it over with then leave, and so I became a recipient here"

Looking at this case study we can derive several points:

1) The parents were aware and knowledgeable of what the EI programme is, based on their reading through the internet, they also approached the programme intending to take on an active role and learn as much as they could to support their child.

This constitutes their level of knowledge which could be described as sufficient.

2) The parents' expectations can be described as positive, because they started the programme with a plan to attend the sessions and learn as much as they could to follow up at home. Later when they were faced with a difficult scheduling situation they sustained this positive attitude by arranging their work schedule around the sessions time table even though it was causing them difficulties at work.
3) The expectations of the parents included their understanding that when they would make a suggestion the EI team would accept it, in a way this expectation falls under their definition of their role, which the father described as (partners). This part of their expectation can be described as

their belief in affecting change, which is one of the elements of empowerment.

4) The initial engagement of the parents in the programme was described as active or as “partners” by the parents, they attended sessions, worked hard to learn, and followed up at home. Their active role continued by their efforts to cooperate with other parents to prepare a plan designed to change the scheduling system so their struggles with planning weekly schedules will be avoided.
5) The parents’ engagement changed to a passive role following the reaction of the staff to their suggestion, and the conflict that resulted. This change happened when the parents realised they need to change their expectations from this programme, and they needed to adjust their role to fit with the expectations of the EI team.

These points could be presented in the following illustrations; the first presents the power dynamics during the first year (before the conflict) from the point of view of the parents:

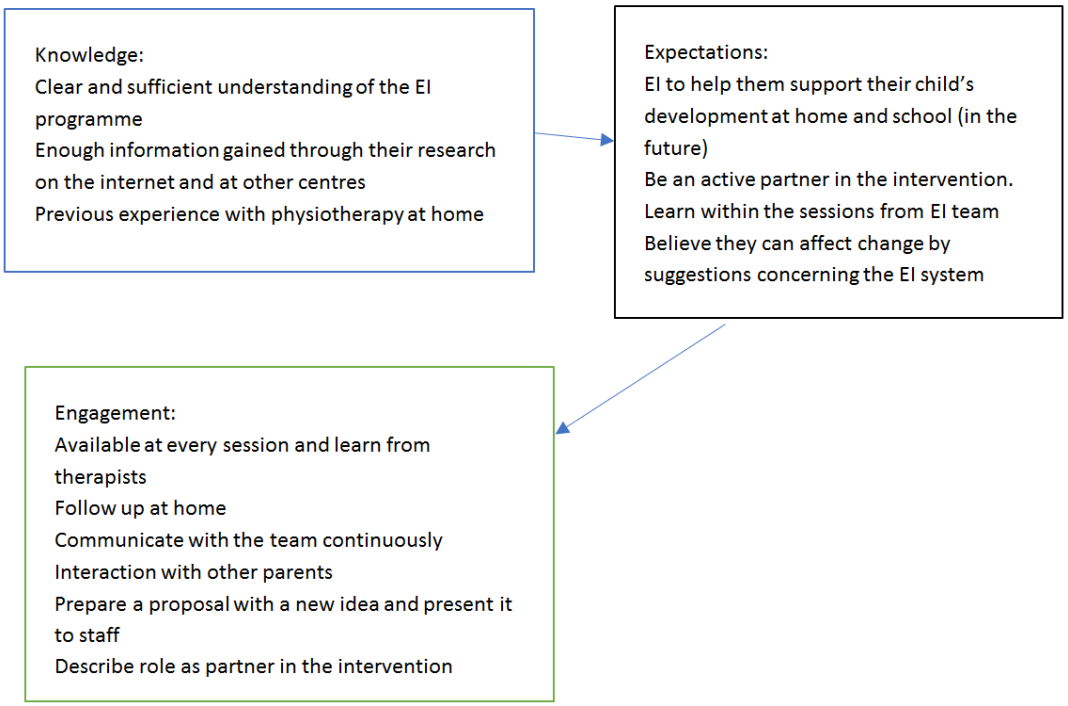


Figure 21: Parent role prior to the Conflict of power

When the conflict happened there was a direct change to the parents' engagement and expectations as reaction to the team's change in attitude, the parents changed their expectations to meet those of the team:

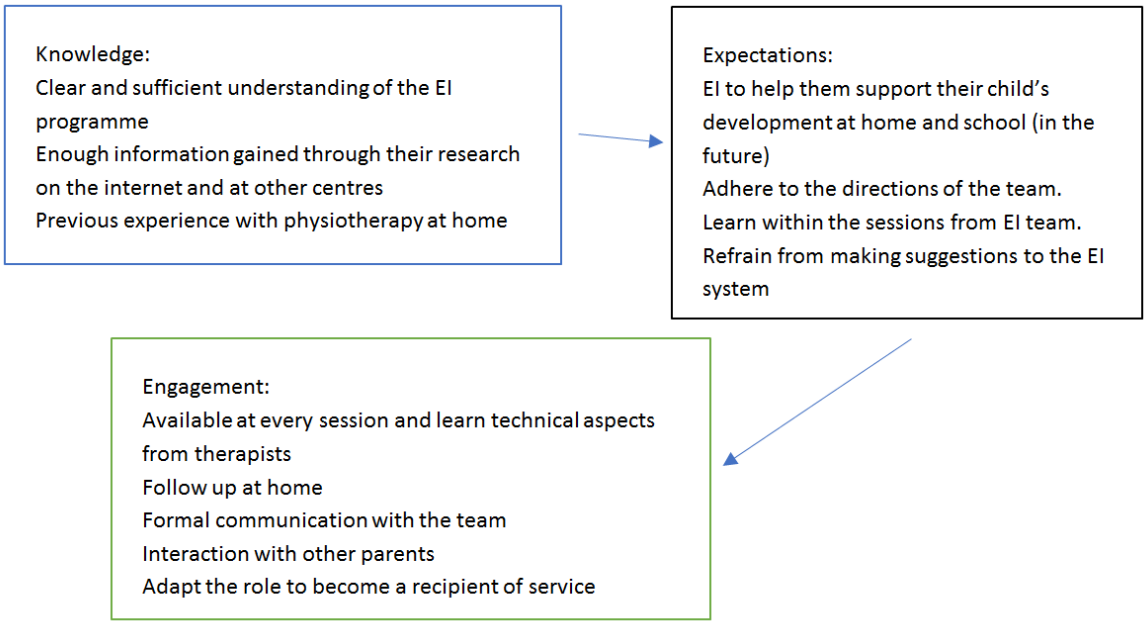


Figure 22: Parent role after the Conflict of power

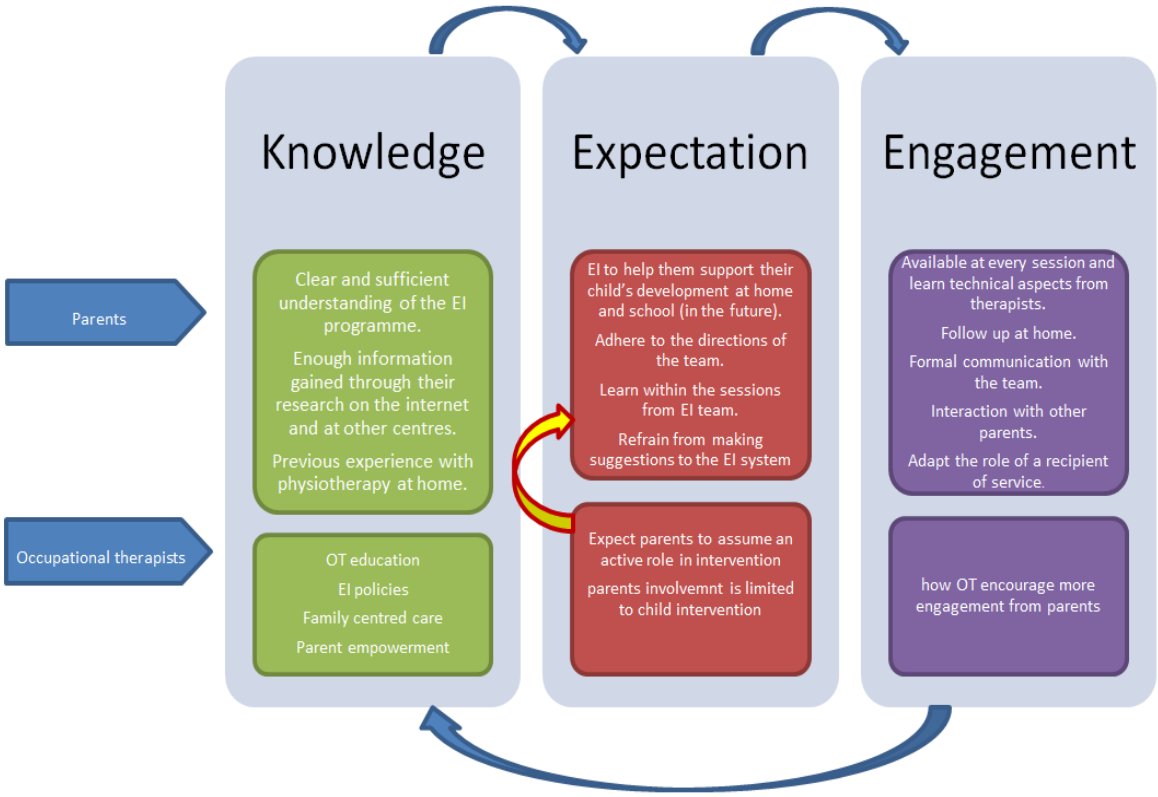


Figure 23: Power scale elements - Conflict of power

It is interesting when we look at this case to identify three main findings:

1) The impact of knowledge is evident at forming the initial expectations and the initial level of engagement, however; during the intervention the impact of knowledge decreases and the EI team's expectations will begin to have a direct effect on the parents' expectations and engagement.
2) When we compare the two figures (Figure 21 and 22) we can see that the participation in sessions, learning technical aspects, and follow up at home was NOT affected by the conflict. But the parents' role has changed to focus only on their direct role with their child, and their role as partners in the

programme, especially their ability to have a voice in the EI programme design was eliminated.

3) The parents labelled their role to be "partners" when they thought they can be heard, that is; when they believed they can affect a change on the programme. When this was taken away from them they perceived their role as "recipient". This in itself indicates the emphasis these parents gave to their ability to speak up and change the system, and them perceiving it as essential to be actual partners in the EI intervention.

When we represent these findings using a (Power scale) framework we will have a distinct shift in the power dynamics:

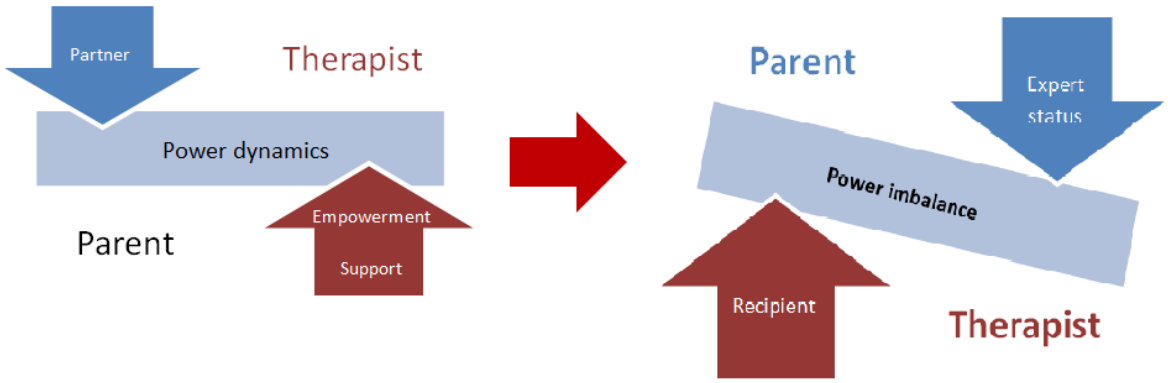


Figure 24: Conflict in Power - shift in power

What caused this shift in the power balance is the team's declaration of their "expert role". This was shown when they used their authority in cancelling the session to show their displeasure, and thus sent an indirect message to the parents that when challenged they can take away the comforts they had previously given the parents when they were adhering to the team's expectations. This message was heard by the parents who shifted their expectations so they could meet those

of the team, thus giving up the part of their role which offended the “experts” and accepted a lower level of power in the EI programme.

This example highlights the possible difference between engagement and participation, referring back to the description of the parents’ engagement when they started the programme we can see two levels of engagement; the physical engagement which is clearly evident with parents’ attending all intervention steps, taking an active role in learning the needed technical aspects, and following up with the intervention at home. The second level which revolved around affecting a change in the EI system based on the needs of the family was initially achieved when the parents came up with their suggestion, had opportunity to discuss it with other parents, present it to the programme manager.

At the start of the EI programme both levels of engagement are achieved, it has a participatory aspect, and an advocacy or empowerment aspect as well, which possibly makes it qualify for a full engagement in the intervention. But when we look at the parent’s engagement after they have been faced with the conflict with the team, and the following repercussions of it, we can see that the physical level has remained, but the empowerment level was eliminated, which changes this from a complete engagement to participation.

It is important to highlight here that this participation level was acceptable to the EI team, who viewed the parents’ role to be limited to the physical aspect of engagement, and according to the parent had described the second level (affecting change on the EI system) as interfering in their work responsibilities. This challenge to the second level of engagement could be linked to two possible reasons:

1) Protecting the “expert” status which was challenged when the parents wanted to affect change themselves without asking the EI team to do that for them.
2) Perceiving the parents as outsiders to the EI programme, or possibly clients, which make their suggestion to change the system as outsider interference.

6. Chapter Six: Discussion

6.1. Introduction:

The role of literature review in grounded theory has been discussed and debated thoroughly since the beginning of this methodology (Thornberg 2012), with three main leaders in grounded theory taking on different perspectives. Glaser (1978) advocated a tabula rasa position where the researcher enters data collection and analysis with no preconceived ideas or theories, this position has been described as an adaptation of the positivist epistemology of not contaminating data with bias. However Straus (1997) who initially agreed with Glaser (1978), later acknowledged the unpracticality of such a position, suggested a limited review of the literature, mainly to support the researcher in deciding on the research aims and question. Constructivist grounded theorists including Charmaz (2014) took on a different position towards a literature review, by highlighting the benefits of using preconceived ideas and a literature review within the data analysis. Charmaz (2014) advocated for the careful use of this stage by the researchers, who are capable of maintaining a scientific and reflective awareness of the influence of their preconceived ideas on the data.

In my study I was challenged by these three different perspectives on the literature review. My position as an experienced EI therapist eliminated the possibility of entering the research with a blanc page (as Glaser invites), and with my extensive study of family centred practice theories and EI models as part of my practice, the position of Straus was similarly inappropriate. This left me with the perspective of

constructivist grounded theory, an option that did have its appeal in terms of the acknowledgment of preconceived ideas and the emphasis given to researcher's ability to maintain a distance when needed.

In the following chapter I will be presenting a targeted literature review of pre-existing models and theories in the field of EI and family centred approach, my use of the word "targeted" here is intentional as I have purposefully reviewed the literature using the grounded theory technique of theoretical sampling, where I have proceeded with a general literature review during the data analysis process and used my emerging findings to direct my search of the literature, delving into areas that reflected the resulting categories, then returned to the analysis to expand the process of understanding the views of my participants. This process is termed theoretical sampling of the literature (Thornberg, 2012) and it required an ongoing understanding of what the participants were actually saying, and what the literature was presenting, with careful awareness and reflection so these two sets of data do not merge but move on a parallel path, leading to a rather condensed literature review that integrates the main emerging themes.

The resulting themes from data analysis were discussed in Chapters three and four, and the final framework was discussed in chapter five. In the following chapter I will present three main themes combined with the literature review and discussed to position the findings from my study within this literature, emphasising how the resulting themes might fill gaps, provide a critical perspective or support existing theories. The three themes are: 1) Power dynamics and the therapeutic

collaboration, 2) Cultural sensitivity in occupational therapy and family centred model, and 3) The impact of language on parent-therapist collaboration.

6.2. Power dynamics and the therapeutic collaboration:

Power is a complex phenomenon categorised in the literature into different types depending on its source, be it power through information, property, or social status (Morrall, 2009). Of most relevance here is expert power, this is linked to the knowledge and skills of a person or a group of people (such as health professionals within a medical setting) which enables them to take on an authoritative position in a relationship with people with less knowledge or skills. The practice of this power could take on an overt or covert style, but would ultimately be effective in declaring who is in charge within the power relationship. For example; in a medical situation expert power is displayed through a demand for adherence from the patients to the commands of the doctor or health professional, this demand could come in the form of the organisational structure of the clinic or through the directions from the staff (Lawlor and Mattingly, 1998b). On the other hand; more subtle ways to express this power can be as effective, examples include: 1) the use of professional language with terminology beyond the understanding of the client (such as: Latin names for body parts or diseases), 2) the professional image of the expert which includes wearing a white lab coat or adopting a formal manner by sitting behind a desk when communicating with the client, or 3) the use of medical technologies such as stethoscope or specialised tests and equipment to show the advanced knowledge of the expert (Morrall, 2009).

In my study, I have collected data through observations of interactions between therapists and parents, reviewing EI records, and interviews with both parents and occupational therapists. The intention behind this variety of data resources was to gain an understanding as I could of the parent-therapist collaboration, through the study of these interactions and the perspectives of both involved parties. The findings from collected data revealed both overt and covert expressions of power by the EI team and at the same time the different responses of parents to these expressions of power. I have used the term power dynamics to reflect the fluidity of expressions of power, as I have noticed variations depending on the persons involved and the context of the interaction, for example, power was expressed at times in a clear manner, while in other instances it was subtly hinted at by the parents or therapists.

6.2.1. **Overt expressions of power:**

There is a consensus in OT literature regarding the definition of a "client" and the central importance of using client-centred practice, however; the issue of power within the client-therapist relationship is still undergoing various discussions (Rodger and Kennedy-Behr, 2017). The therapist is expected to build and maintain a cooperative relationship with the client placing them both on equal levels of power, specifically regarding the power to make decisions. However; there is a clear distinction between the therapist's efforts to *exert power over* the client, which entails the client's adherence to this power and the therapist's authority over the client, and the therapist's efforts to *give power to* the client, which would

shift the role of the therapist from the expert to the partner in this client-therapist relationship.

This clear distinction between (*power over*) and (*power to*) is complicated by different factors, including but not limited to the institutional culture, which frequently disempowers the client, and affects their ability in taking over the decision making process, this is especially evident within institutional cultures that still adopt the medical model or are still moving gradually towards a family centred model (Hanna and Rodger, 2002).

6.2.1.1. Access to Early Intervention records:

During the first phase of my study I looked at the records of the EI programme to understand the context within which parent-therapist collaboration operates. My notes on the EI records revealed the steps of the intervention process including assessment, planning, documenting progress, and discharge. However; the records seemed to be designed for the use of the EI team mainly, with sections for therapy plans and progress notes for each staff member, and one main family support plan which is written also by the EI team. The structure and content of the EI records did not seem to cater to the parents' understanding, with the majority of the records written in English and using professional language.

During the interviews with the parents I asked them if they had a chance to look at their child's EI records, but none of the parents knew there was any EI record specific to their child. This finding reveals one facet of power dynamics in the parent-therapist collaboration. At the start of the EI programme parents are given documents to sign (the legal contract between the EI programme and the parent),

they are also told of the main EI goals for their child's intervention, however; during the programme which could continue for 2 or 3 years, the parents are not privy of their child's documented plan or progress notes, this kind of information is reserved for the professional team. Access to this kind of information would allow parents to monitor the intervention as an actual partner (Dunst, 2002, Dempsey et al., 2009, Dempsey and Keen, 2008, Bamm and Rosenbaum, 2008), but denying them this monitoring role places the parents as recipients of the service with no authority to criticise or question the authority of the EI team.

In an expert power relationship, the expert retains knowledge which places the other party in the relationship in constant need for the assistance of the expert (Morrall, 2009). The review of EI records in my study revealed this when I saw that the documents were written mostly in English language, apart from the legal documents. Several sections included professional terms that are used by the team, which meant that parents would have a challenging time to read it even if they knew English language. If a parent wanted to access their child's record to understand what the therapy goals are or how their child is progressing they will need one member of the team to explain it to them, which simply places the parent as dependent on the EI team.

6.2.1.2. Parents as experts of their child:

The structure of the EI records is a concrete representation of the EI programme's vision of the role of parents and therapists. The parents are asked to commit legally to the policies and rules of the programme, they are assigned the role of recipients in the intervention, and not given the power to monitor the EI intervention, nor

participate actively in the overall planning (which was documented fully by the therapists in English in separate plans). In fact the input of the parents in the EI records was limited to a list of their priorities for the intervention. This is a clear deviation from the principles of family centred practice, where the parents' ability to enrich the decision making process with their knowledge of contextual issues, their expert perspective of their own family situation and their specific occupations, and their constant involvement in the process of the intervention are all necessary to foster a partner role within the intervention (Hanna and Rodger, 2002).

Studies that looked into the perspectives of the families towards their communication with the therapists report some challenges, especially in terms of not being heard about their child's situation and needs. In a study by Kruijsen-Terpstra et al (2016) where 21 parents of young children with Cerebral Palsy were interviewed regarding their perspectives of their collaboration with occupational and physiotherapists, one of the main themes discusses partnership between the parents and therapists, and the participants expressed their need for the therapists to listen to them and accept their knowledge of their own child. In this study Kruijsen-Terpstra et al. (2016) parents expressed their need for communication through a variety of methods, not only written but also face to face, especially when relating to the progress of the child. This variety of needs relates to the variety of families and personal communication styles (Kruijsen-Terpstra et al., 2016)

In my study, the design of the EI plan and other documents in the EI records focused on the observed needs of the child from the perspective of the therapists, while the parents' input was limited to listing their priorities in the intervention and the main challenges they face at home. This design reflects again the expert power, while the parents have an abundance of knowledge of their child and the family interactions, which are essential information for a family centred practice (Hanna and Rodger, 2002), this knowledge is not included or documented, whereas; the therapists document their detailed observations of the child as important information required to plan the intervention. It is important to clarify here that I have observed the therapist asking the parents questions about the child during the assessment session I observed, but the absence of documents to record these information hints at the value given to the parents' knowledge of the child.

A possible explanation for this absence is potentially based on the term 'medical gaze' introduced by Foucault (2002), where an expert utilises their professional theories and knowledge to select what they deem as important from their patient's description. Thus, the therapists in the EI programme pick and choose the information they consider is important and relevant to the child's intervention, and disregard the rest, using their position as professional experts to decide on what is potentially useful to be documented, and thus exercise their expert power to filter information. It is safe to conclude that the knowledge of the parents, be it regarding their child or their family as a whole, is not explored extensively but rather approached as supplementary to the direct observations of the expert staff.

In the study by Kruijsen-Terpstra et al. (2016), the findings indicated a common need from participating parents to acquire information regarding their children's diagnosis and future development, as well as their role within the intervention. The parents revealed a link between empowerment and the information they were asking for or receiving. At the start of the intervention parents needed general information about their child's diagnosis, but as they became more involved and had opportunities to discuss with other parents they became more specific in the kind of information they asked for, and they also described a better understanding of how to form goals for their child's intervention.

The study by Kruijsen-Terpstra et al. (2016) also revealed a direct link between information and assuming a partner role in the intervention. At the start of the intervention parents reported they relied more on the therapist to make the decisions and set goals, however, as they acquired more information on their child's situation and the intervention they became more involved in the goal setting. On the other hand; participating parents reported different views concerning their role within the intervention, some preferred the therapist to be the leader due to their level of expert knowledge, and because the parent trusted the therapist to make the right decisions. Although these variations were mentioned in the findings it was not clear how these differences impacted the findings. The authors indicated that contextual factors had an impact on the experiences of the parents regarding empowerment, but no clear discussion of these contextual factors was evident.

The variations in parents' involvement in the intervention revolved around the perception of the parents towards their own knowledge; those who perceived themselves as lay people wanted to depend on the expert knowledge of the therapist, while others who saw themselves as experts on their child were more inclined to an active role in the intervention. This variation is again linked to knowledge and the perception of what type of knowledge the parent needs to become a partner in the intervention (Kruijsen-Terpstra et al., 2016).

In Occupational therapy practice the impact of adopting a client-centred philosophy is seen in relying on the knowledge of the client, using interview skills and various assessment tools to clarify the needs and priorities of the client, in an effort to form a picture of what the client knows and wants, this philosophy then places the client at the centre with the power to lead the intervention process by clarifying their needs and expectations. Taking this perspective into paediatric OT we might see some difficulty in applying this core philosophy as the client in this case is the child, that is when family centred practice becomes essential, as therapists use this same philosophy and core skills such as interviewing and collaborative goal setting to gather information on the needs of the family as a unit, and clarifying their preferred form of involvement within the intervention.

6.2.1.3. Organisational structure of the Early Intervention:

Organisational structures and policy are identified as potential limitations or facilitations of the implementation of family centred practice (Bamm and Rosenbaum, 2008). Among the evident signs of an organisational commitment to family centred practice is the involvement of families in the design of the

programme as a whole, and a clear inclusion of family centred practice within the mission statement and programme philosophy (Darrah et al., 2012). The term "clinic culture" (Lawlor and Mattingly, 1998b)page 262) describes the impact of the environment within which occupational therapists work, which include policies and organisational structure that foster a medically based model, thus; when the therapists attempt to use family centred models within this environment they are challenged by the structure itself which hinders their efforts.

In my review of the EI records I had the chance to examine the legal contract signed by every family as part of their EI programme. This document represented the organisation's view of the role of the family in the intervention, and it was clear that the parents are to perform the role of assistant and adhere to the instructions of the team, which placed the power in the hands of the team. At the same time; this legal document, which is signed at the start of the programme clearly defined the expectations of the organisation, and consequently spelled out the role of the parents.

> In the legal document signed by the parents there is one rule stating: *the parent is the assistant of the team, they adhere to the professional recommendations, and they follow programmes sit by the team*. I can't help but place myself in the parents' shoes when they read and sign this, wouldn't they just see their role as assistants?
>
> Reflection- EI records (lines 30-34)

In the interviews with parents they described their expectations of the therapist to be the "expert", then discussed their role using words such as assistant (مساعد

Mosaed) with frequent references to their efforts to adhere to the instructions of the therapist. This description reflected the therapists' *power over* the parents by directing them both within sessions and later at home. The impact of the legal document parents sign at the start of the EI programme is evident here, as they describe their role in EI within the same outline stated in the legal statement mentioned above, thus, it is possible that because parents were introduced to this specific version of their role in the EI programme early on, they have adopted this view as part of the design of the EI programme and took it as the expected role they should assume.

Family centred practice is essential for paediatric occupational therapy (MacKean et al., 2005, Rosenbaum et al., 1998, King and Chiarello, 2014), and the key principles of this practice highlight the importance of knowledge, communication, and active partnership between the therapist and the parents (Kuo et al., 2012, King and Chiarello, 2014, Rodger and Kennedy-Behr, 2017, Hanna and Rodger, 2002). For parents to assume their role as partners in the EI they require access to technical information regarding their child, they need to input their knowledge as experts of their children, and the organisational structure of the EI should delineate the active role of the parents.

6.2.2. **Covert expressions of power:**

The power dynamics within the parent-therapist collaboration were also evident through indirect expressions, which were observed during sessions or discussed in

the interviews with participants. In the next section I will be presenting these covert expressions to complete the picture of power imbalance within the parent-therapists collaboration in EI.

6.2.2.1. Occupational therapists and role dissonance:

During the interviews with the therapists they described their strategies to promote parent collaboration as an essential part of their role, they emphasised the importance of helping parents become true partners in the therapy. However, their descriptions of their efforts included using language that suggested again *power over* the parents, examples given in the findings in chapter four include words such as 'appease -نسايِر Nesayer' and 'blind trust', which indicate a position of power that directs the collaboration in the direction which the therapists deem correct. At the same time; the therapists also expressed their frustration with this kind of power dynamic, by describing their efforts to encourage the parents to be more involved but facing resistance because parents wanted them to be in charge. It was evident that the therapists were struggling with a dissonance between their anticipated role in the FCM and the reality of their role. Their struggle was potentially related to the confusion they face between what they have learned in their formal education as OT students, and the actual application of this knowledge in real work situations. The therapists were describing situations where they tried to change their role in the collaboration from being an expert to a facilitator or partner in the intervention, however; this transition was impacted with the role dissonance they were experiencing.

Similar findings were reported in a study by Malkawi et al. (2020) to investigate the influence of culture on the practice of occupational therapy in Jordan, where 11 OTs were interviewed, and participants expressed frustration with the lack of knowledge about the role of OT which was attributed by authors to different factors including the difficulty of translating OT core concepts to the Jordanian community, this impacted the practice of the therapists who had to make changes to their role and find a middle ground between the expectations of their clients and the theoretical foundation of their practice (Malkawi et al. 2020).

This shift in the therapist's role from expert to partner is further compounded by the challenges that face the therapist, which reportedly might include difficulties in engaging parents in the goal setting process and later the intervention, particularly in relation to the needs of the family as a whole (An et al., 2019). These challenges are sometimes evident in a conflict between designing the goals based on the therapists' own expert knowledge, especially in paediatric programmes, as opposed to listening to the family's opinions and setting the goals according to their needs. At times this conflict is highlighted when the therapist's knowledge and expertise is in clear conflict with what the family regards as essential in the goals, a situation that was described by a sample of 16 occupational therapists and physiotherapists in a study by Graham et al (2018), who discussed instances of disagreements with caregivers when the therapists recommended certain strategies that the caregivers did not want. Such disagreements are not uncommon when implementing family centred practice (Rodger and Kennedy-Behr, 2017). Nevertheless, accepting the caregiver's opinions within family centred practice is

considered as an indicator of sharing power, and a clear shift of the therapist's role from an expert to a partner in the therapy (Graham et al., 2018).

6.2.2.2. The "ideal" parent role in FCM vs. reality:

In the power imbalance theme (in chapter 4 and page?) we saw different elements that revealed this dynamic, starting with the expectations of the parents from the EI programme, especially at the start of the intervention. Parents emphasised their expectations of receiving therapy service from the specialists because *"they are the experts"*. References to the therapist's knowledge and expertise was dominant when the parents were asked about their involvement in the intervention, they highlighted their expectations from the "experts" who would tell them what to do, and they stressed their trust in the experts' knowledge because *"she knows better than me".*

The role of parents in their child's care has evolved from the passive role of receiving orders from the expert which was dominant in the medical model, to the involved parent who is guided by the specialist to apply therapy at home, and finally reaching the more "ideal" role within FCM of an empowered parent who makes the decisions and collaborates with the therapists on an equal standing (Hanna and Rodger 2002).

The transition in the parent role from passive recipient to empowered partner is still not achieved fully according to the literature (Law et al., 2005, Hanna and Rodger, 2002, Franck and Callery, 2004). In fact, studies that looked into the perspectives of parents such as (MacKean et al., 2005, Dodd et al., 2009, Kruijsen-Terpstra et al., 2016) revealed a preference some parents had to being involved in

the planning of the intervention only to a certain extent, and to continue to rely on the expertise of the therapists in choosing the treatment programmes and the implementation of the therapy. This preference was linked to parents' view of themselves as "lay people" who couldn't have the technical knowledge or experience to make treatment decisions even if therapists provided such information (page 318, Kruijsen-Terpstra et al 2016).

In a study by Dodd et al. (2009) where thirteen families were interviewed regarding their relationship with allied health professionals, the findings revealed a need for parents and professionals to achieve shared understandings or expectations at the start of the intervention, which would enable the parents to participate in an equal partnership. This specific finding resonates with some of the views of the parents in my study, who described their involvement as active by giving examples when therapists would tell them the goals or the priority of the intervention. This level of involvement might not reach the "ideal" role within FCM where the parent is expected to have the final say in terms of the treatment goals, while the therapist assumes the role of supporting this decision making process with information, but this level of involvement could be satisfactory for the parents.

In other words, the available literature on the perspectives of parents concerning FCM such as (Dodd et al., 2009, Kruijsen-Terpstra et al., 2016, MacKean et al., 2005) advocates allowing families to decide on the level of involvement or their role within the intervention depending on their needs. For those who consider themselves as "lay people" and prefer to be guided by the experienced professional, then it is in fact empowering to adhere to their preference and needs

as family. This also means that parents who want to be involved in a more active role, those who want to be partners in the intervention, they should be allowed to do so by the therapists, whose responsibility is to give up their "expert" authority and work on an equal power level with the parents.

6.2.2.3. Expert power vs. making suggestion:

Another covert indication of the power dynamics was revealed in one interview with a parent, who expressed their frustration with the EI team for rejecting a suggestion made by this parent, then changed their attitudes towards this family and *(took my suggestion as interfering in their work),* this was discussed in Chapter four under subtheme (Challenging the expert page 132). Because the suggestion made by this parent related to the organisational structure of the EI programme it reflects the parent's attempt to affect change on the programme which indicates their role as an active partner in the intervention. However; the team's reported response reflects their preference to maintain their role as "expert" and view this suggestion as interference in their power. This example represents power dynamics between a parent who wants to assume an active partner role in the intervention, but is prevented by the defensive attitudes of the team who reportedly did not want to give up their power, at least not to this particular parent.

Power dynamic within parent-therapist collaboration has an impact on the roles each party takes within the early intervention programme, that is why one of the most essential elements of family centred model is the parent-therapist collaboration (Rodger and Kennedy-Behr, 2017, Hanna and Rodger, 2002). My study has examined the manifestations of power dynamic be it overt or covert,

with the aim of forming an understanding of how parent-therapist collaboration develops, and ultimately what factors impact this collaboration. As a result of this study I have designed a theoretical framework that looks at the power dynamic in this collaboration and explains its elements, then provides an explanation of how this power dynamic could be shifted through manipulating its elements. This framework (power scale) was explained in chapter five with examples from my study to illustrate the use of the framework to move an unbalanced collaboration into a balanced one.

6.2.3. OT core skills and the parent-therapist collaboration within EI:

Occupational therapy as a profession promotes a client-centred perspective, and uses a multitude of core skills to promote the positive collaboration between the therapist and the clients. These skills include therapeutic use of self, motivational interviewing, and collaborative goal setting. Within early intervention occupational therapists are expected to empower, teach, and support families as an evidence based practitioner to facilitate child's development (Clark et al. 2004).

In this section the parent therapist collaboration is unpacked by looking at the OT core skills, starting with the therapeutic relationship within the occupational therapy literature, which could provide us with the general perspective on the impact of a positive therapeutic relationship and the possible challenges to it. We can then move on to look specifically at how occupational therapists use various skills and information to form and encourage positive collaboration with their

clients, leading us to the more specific form of therapeutic relationship used within EI programmes which is the parent-therapist collaboration.

The therapeutic relationship between the client and the therapist is considered as an essential aspect of the client centred practice within occupational therapy. It is defined as a trusting and respectful connection between the therapist and the client, which is built through professional communication, collaboration, empathy, and mutual understanding (Cole & McLean 2013). According to Taylor (Renée R Taylor, 2008) there are several elements to this therapeutic relationship that need to be considered, which are described within the Intentional Relationship Model IRM, including; 1) the client, 2) the interpersonal events that occur during therapy, 3) the therapist, and 4) the occupation.

In the IRM the therapist is responsible for understanding the client, and using different opportunities to encourage positive interpersonal events which would lead to a strong and positive therapeutic relationship. One of the skills the therapist utilises to this purpose is therapeutic use of self, where the therapist becomes aware of their own interpersonal capacities, including a variety of therapeutic modes, which are ways the therapist could use to relate to the client (Renée R Taylor, 2008). The IRM identifies six different therapeutic modes: 1) advocating for the client's rights and negotiating to secure needed resources, 2) collaborating with the client by ensuring they take an active and equal role within the therapy, 3) empathising with the client to understand their thoughts and feelings, 4) encouraging the client throughout the therapy and celebrating their successes, 5) instructing therapy activities to the client and explaining the therapy process, and

6) problem-solving by providing the client with choices and opportunities to develop pragmatic thinking.

The role of the occupational therapist within a family centred early intervention programme is described in similar terms as the above mentioned therapeutic modes (Hanna & Rodger, 2002). It is essential for the therapist to work on developing a positive collaboration with the family within the early intervention, by being an advocate for the child and family rights, and helping the family to learn the different skills they require to facilitate their child's development. This can be achieved by providing the family with solutions to their daily problems, and empathising and empowering them throughout the therapy process to be true partners in the intervention.

The development of a therapeutic relationship within any occupational therapy programme is similar to the development of a family-therapist collaboration within a family centred early intervention programme. The therapist is expected to assume different roles or modes to facilitate a positive therapeutic relationship, and according to the literature when this positive therapeutic relationship is achieved it will impact positively on the success of the therapy intervention (Anderson & Hinojosa, 1984; Case-Smith & O'Brien, 2014; Rodger & Kennedy-Behr, 2017). But what are the challenges therapists face to achieve this positive collaboration? In the following section we will review different studies that looked into the therapeutic relationship or family-therapist collaboration, in an attempt to understand the possible challenges that therapists face.

One of the possible challenges to a positive therapeutic relationship we see discussed in the literature is the position of the therapist when entering this relationship. According to Anderson (1984) it is common for therapists to assume an advocate role on behalf of the child when they begin an intervention, a role that implies they (the therapists) have more knowledge and skills that qualifies them to know what is best for the child. This position immediately constructs a hierarchy within the intervention which would hinder an equal footing within the therapeutic relationship, thus directing the family to depend on the authority of the therapist when making decisions or planning (Rodger & Kennedy-Behr, 2017).

The different perspectives of the family and the therapist influences the expectations from the therapeutic relationship and this in turn has an influence on the nature of this relationship (Hanna & Rodger, 2002). Families come into the intervention with their own individualised perspectives, culture, and background, while the therapist perceives this relationship from a professional perspective that is influenced by their knowledge and personal background. If there is no attempt to understand and accept the family's unique perspective from the therapist's side, then this relationship would include misunderstandings or negative interpersonal events, which would in turn limit communication and as a result affect collaboration (Anderson & Hinojosa, 1984; Hanna & Rodger, 2002). The therapists are however prepared with a variety of skills to use empathy and different types of interviewing styles to collect information from the family. These skills support the therapist's position as facilitator of the therapeutic relationship, while maintaining a focus on the families' unique needs and background.

When describing therapeutic modes Taylor (2008) gives a special emphasis to the cultural and social background of the client. She invites therapists to consider the possibility that clients coming from different cultural backgrounds especially those with a dominant medical model where the expert is expected to provide information and make decisions. Those clients might in fact need the therapist to be more informative and provide them with solutions, rather than attempt to encourage the clients to take an active role in therapy. Taylor (2008) explains the necessity for therapists to understand their client's needs, and to change their therapeutic mode accordingly, even when the therapist's inclination is different. She explains that the therapeutic relationship is more likely to be successful when the therapist adopt their therapeutic mode according to their client's needs.

Studies that looked into the perspectives of the families towards their communication with the therapists report some challenges, especially in terms of not being heard about their child's situation and needs. An example of this is the study by Kruijsen-Terpstra et al (2016) where one of the main themes illustrates the parents' expressed need for the therapists to listen to them and accept their knowledge of their own child. The parents in Kruijsen-Terpstra et al (2016) study also identified their need for encouragement from the therapists, which is interestingly one of the therapeutic modes described by Taylor (2008) within the intentional relationship model and discussed previously.

Although there is an agreement in the occupational therapy literature regarding the impact of therapeutic use of self on the development of positive therapeutic relationships (Anderson & Hinojosa, 1984; Case-Smith & O'Brien, 2014; Hanna &

Rodger, 2002; Renée R Taylor, 2008), there is also agreement on the need to support therapists to develop needed skills in this area. In a study that surveyed 568 occupational therapists in terms of their training in therapeutic use of self, Taylor et al (2009) reported a general agreement among the participants on the importance of therapeutic use of self within their practice. However, most participants indicated the need for more knowledge on using the self therapeutically and therapeutic relationship, in fact about half of the participants felt they were not sufficiently trained in this area. Although the participants in this study worked in all the different areas within occupational therapy practice, these findings give an indication of the importance of dedicating training to support therapists to develop skills in forming therapeutic relationships.

The results from my study indicate a need to facilitate the therapeutic use of self within the formation of parent-therapist collaboration. Therapists use communication skills, and different types of interviewing skills to collect information from the parent, and to understand the particular needs of the family, thus building a foundation for the collaboration which is designed to fit the needs of the family as a whole.

6.3. Cultural sensitivity in Occupational therapy:

Culture has different definitions in the literature (Schein, 1991), with some focusing on race and ethnicity as the primary determinant, while others include other aspects of diversity such as socioeconomic status, gender, religion, and ability or

disability (Hammell, 2013). In Occupational therapy, culture is defined in relation to meanings that reflect on occupation, and Iwama (2004, p. 1) uses this definition to illustrate the diversity of culture as: “Shared spheres of experience and the means through which **meaning** is ascribed to the objects, phenomena around us”.

Our repertoire of meanings which we assemble through our lives is coloured by our cultural background, and thus; our understandings of knowledge has its foundation in our cultural meanings. Foucault (2002) criticises the notion that there is one universal truth capable of surpassing the diversity of perspectives and understandings. He asserts the privileges which a universal truth would give to one agenda while excluding the others. This perspective hints at the presumption theories would have towards the cultural backgrounds of its creators, which means theories are coloured by the meanings and assumptions residing in one or another culture. Hammell (2019) discusses the cultural hue of occupational therapy theories which are embedded in Western white middle class culture, thus; impacting on the fundamental concepts of the profession by limiting their meanings to values and understandings belonging solely to the Western cultures. The development of OT approaches and models has been affected by this same cultural hue, making theoretical assumptions within these models to belong and be more relevant to therapists originating from Western cultures (Iwama, 2006, Hanna and Rodger, 2002).

6.3.1. **Family centred models in Paediatric Occupational Therapy:**

The role of the family within early intervention (EI) programmes has undergone different changes over the past 50 years. In the mid-1970s a child-centred model was used more dominantly, placing the focus of the EI programme on the child as a separate entity from the family (Edwards et al., 2003). And as the family centred model emerged in the 1990s the family were assigned the role of a catalyst for the child's developmental progress (Thompson, 1998), introducing a change in the design of EI programmes to include the whole family as a unit. However; with this major change in the model used in EI, the roles of professionals and the families within the programme needed to be adapted, which initiated a discussion within the literature concerning how to facilitate this transition (Rodger and Kennedy-Behr, 2017).

Family oriented models are described in the literature as different models used within health care programmes, Dunst et al (2002) built a framework to explain the main characteristics of these different models, it describes a continuum where on one side there are models that set the professionals as the centre or leader of intervention, and on the other side family is perceived as partner and leader of the intervention within Family centred models . Among these models the literature describes the medical model, family allied model, the family focused model, and family-centred models. All of which describe different variations of collaboration between the parent and the professional, starting with an expert led collaboration to a partnership where both parent and professional work together equally (Hanna and Rodger, 2002).

Likewise; Brown (1997) has described a 7 level hierarchy that describes parent-professional collaboration from the perspective of the parent, with an emphasis again on the occupational therapists' attitudes and beliefs within each level. This is a similar description where the collaboration is presented through the lens of the professional, while the family role is discussed as a result of how professionals initiate the collaboration. The following table demonstrated the 7-levels hierarchy:

	1	2	3	4	5	6	7
	No family involvement	**Family as informant**	**Family as therapist's assistant**	**Family as co-client**	**Family as consultant**	**Family as team collaborator**	**Family as director of service**
Interaction	Only if essential of by accident	Family interview to obtain information	Educating them about disability and how to follow up	OT is concerned with how well the family is coping	Family are asked for input on goals but not a team member	Family included in assessment, goal development, and intervention planning	Family decide if OT is involved, family is team leader
OT attitudes and beliefs	Biomedical approach, family is seen as interfering with or distracting	OT acknowledge family has useful information, focus on client's history	Decisions are best left to therapists, family instruction to ensure continuity. Lack of follow up could impact on intervention	Family abilities and needs may lead to an adapted intervention plan	Family affect the client, family has insight into what will work. Family input to target needs most meaningful to client	Increased integration and independence is achieved through family, power is shared with family	Family help member to develop, supporting family function will help client, intervention not directly related to client
OT Skills and knowledge	No knowledge or skill in working with family Good clinical knowledge and technical skills	Interview skills Understanding of human development Impact of culture on a person	Ability to teach procedures to family Teaching and communication skills	Empathetic interpersonal skills Knowledge of family system theory	Understanding of family function, tasks, and development Recognition of cultural factors on family	Family evaluation and skills to elicit participation Collaboration skills Expressed respect for values of others	Consultation skills Knowledge of community services Family centred care philosophy

Table 5: The 7-levels hierarchy for family involvement (Brown 1997)

The benefits of using family centred models within EI programmes stems from the belief that parent-therapist collaboration is more likely to produce relevant and meaningful intervention goals, and thus increase the likelihood of integrating therapy within the child's natural environment, thus; family centred models are considered as best practice within rehabilitation programmes for children (Hanna and Rodger, 2002, Almasri et al., 2014, An et al., 2019).

Another perspective within Early intervention programmes focuses on the professional collaboration. Different approaches such as collaborative teamwork,

Team around the Child, and Transdisciplinary team are focusing of the small group of professionals (including the parents) around the child, and how their working together is essential to support the child and family (Limbrick, 2007). These different approaches complement family centred models which focus support on the family unit, but move further to consider the impact of complex developmental issues that might require expertise from different health professionals. Complex needs cannot usually be appropriately addressed separately but require a strong level of collaboration to tackle such needs comprehensively.

Within my study, the participants in the therapists' interviews were asked about their collaboration with parents within EI; and their answers revealed a gap between what they expressed as a theoretical or "ideal" family centred model and the reality they experienced in their practice, the therapists used setting intervention goals with the parents as an example of how this collaboration commonly progresses, with references to parents who expected the therapists to be in charge and tell them what to do. At the same time, while observations made in my study included attending parent-team meetings, neither parents not therapists within the sample discussed the collaboration between the team around the child, even though this collaboration was observed in the meetings and the assessment sessions. However it was not acknowledged formally as part of the EI system, which might indicate this type of team collaboration is happening informally.

In the study by Malkawi et al. (2020 in press) the Jordanian occupational therapists and physiotherapists working in EI showed similar theoretical understanding of the

main elements of family centred model, with almost half of the 97 participants stressing the need to collaboratively set goals with parents. However, when asked about the priorities of goals used within home programmes, 56% of the sample said they prioritised their own goals over those of the parents. This contradictory finding demonstrates the gap between theoretical knowledge of FCM and the reality of practice. This is congruent with the literature (Edwards et al., 2003; Dempsey & Keen, 2008; Dunst et al., 2014; Klein & Chen, 2008; Roggman et al., 2010) which shows limited application of FCM in practice even though therapists are clear on the elements of FCM and parent role.

The theme (Categorising parents) in Chapter four described the expectations of the parents from the perspectives of the therapists, with an emphasis on the frustration therapists expressed with these expectations. On the other hand, parents expressed clearly their expectations of the therapists to “be the experts” in subtheme (they are the experts) page 118, by referring to their need to get instructions from the therapist because they have the technical knowledge. This picture of the parent-therapist collaboration, where the therapist is the expert while the parent depends on their directions was the most evident representation of the EI in Jordan. It was described by the participants and also observed in the parent-team meetings and OT session in the first phase of my study. This picture resembles what is described in the literature as the medical model (Dunst, 2002, Brown et al., 1997). Almasri et al (2011) looked into the needs of Jordanian families of children with cerebral palsy, and concluded the clear dominance of the medical model within different services in Jordan. They also noted the expressed needs of

the parents in the study for support during the early years of their children's lives, but as "hands-on" therapy services where the professionals provided therapy for the children.

In my study parents expressed similar expectations from EI, they anticipated the therapists to be the "expert" who tells them what to do, and measured their participation in the programme through their adherence to the therapists' instructions. At the same time; therapists in my study explained this attitude by referring to the cultural understanding of the therapists' role, and by discussing the difficulty in understanding the concept of partnering in a therapeutic programme. They saw the application of family centred model as difficult to "fit" with the Jordanian culture, which begs the question: could this dominance of the medical model be due to the cultural understandings of therapy services?

6.3.1.1. Cultural appropriateness of family centred model:

The gap between the theoretical principles of family centred practice and the reality of practice in EI in Jordan questions the cultural appropriateness of FCM. While therapists in my study clearly understood what the FCM requires and they exhibited motivation to apply the principles of the model, they still faced challenges to do so which they attributed to the difficulty in communicating these principles to the families. As a model that emerged from westernised ideologies it is based on assumptions derived from individualistic cultures, including the typical structure of family which is limited to the parents and the children, while in collectivist cultures the structure of the family might include extended family members such as grandparents or uncles and aunts, who would have an influence

on the decision making process related to the child (Al Busaidy and Borthwick, 2012). This point was discussed by the therapists in my study, who explained how they do not necessarily always deal with the parents of the child but frequently work with other members of the extended family, who also have caregiver responsibilities, which expands the definition of family to include other members and thus poses a new challenge of dealing with several family members of different generations. In a recent study looking into the cultural impact on occupational therapy in Jordan by Malkawi et al. (2020) the occupational therapists interviewed described similar observations, as they described dealing with members of the extended family often even when the client is an adult. This reveals a cultural feature in the Jordanian community, namely the connectedness between members of the wider family, and the interdependence commonly seen within collectivist cultures.

At a broader level, family structure is diverse with multiple variations that might not necessarily fall under the social construct assumed in a family centred model including extended family, multiple or single parents (Kruijsen-Terpstra et al., 2016, Hammell, 2013, Franck and Callery, 2004). Similarly; the uniqueness of family is not only linked to their diverse communication style or needs, but moves beyond to their cultural background which has a significant impact on the perception of health care and disability, thus forming the expectations of the family from the EI professionals, and their own role within the EI.

And while FCM highlights the uniqueness of family as discussed by (Law et al., 2005; Rosenbaum et al. 1998) by emphasising the importance of looking at each

family differently, taking into consideration the diversity and different styles of communication based on each family, but the literature still lacks considerations of the cultural impact on the family's perception of EI. At the same time, it is unclear how these considerations can be implemented practically in practice, thus causing the gap reported in literature between theoretical principles of FCM and the reality of its implementation within EI. This makes it necessary to produce more studies from the perspective of non-Western families and therapists, which might shed some light on the impact of culture on the unique position of families (Mahoney & Kiraly-Alvarez 2019).

The impact of individualistic culture on the description of "ideal" family centred model extends further to highlight another element; the role of the family which is framed as the sole authority in the intervention, this role is described with an assumption that families want such role, but we can see here the influence of highly esteemed values in the Western culture which is autonomy, and also the influence of a consumeristic perspective where the intervention is perceived as a business relationship between the "client" and the therapist, a relationship where the client wants to lead because they are "buying" the service. However; this perspective might not fit within a culture where services for persons with disabilities is considered social responsibility (Al-Aoufi et al., 2012), and thus creates a conflict between the 'buy and sell' notion from the family centred model and the 'caring for the invalid' or as described in Arabic (التكافل الاجتماعي Takaful Ijtema'y) which translates into social solidarity (Hasnain et al. 2008).

As a Muslim and Arabic country, the Jordanian culture is derived mainly from Islamic social philosophy and tribal social constructs, which includes the Islamic view on social solidarity (التكافل الاجتماعي Takaful Ijtema'y). This specific concept represents the cultural view towards people in need within the community including persons with disabilities, where individuals of the Muslim community who suffer a disadvantage (physical, mental, or economic) are entitled for support from their community, this support could be financial or social depending on the needs of the individual (Al-Aoufi et al., 2012). The origin of this concept is derived from the teachings and directions from Prophet Mohammad who said: 'The similitude of believers in regard to mutual love, affection, feeling, is that of one body; when any limb aches, the whole body aches, because of sleeplessness and fever' (32, 6258) (Al-Asqlani, 1986)

Social solidarity (التكافل الاجتماعي Takaful Ijtema'y) emphasises the right of the individual (or their family) to access services necessary to them, and places social pressure on community members with the relevant expertise to provide such services. This specific perspective has its foundation in the Islamic doctrine related to health and disability, where care and support is provided for members of the community in need as their rightful due, and providers of such support are practicing their social responsibility for which they will be awarded in the afterlife (Al-Aoufi et al., 2012, Hasnain et al., 2008).

As for the prescribed role of the family within FCM, it is one of the issues that goes beyond cultural sensitivity to the issue of empowering the family, as some studies from Western cultures have indicated similar findings where parents expressed

their need for a different role than what is prescribed in FCM (MacKean et al., 2005). The assumption behind FCM is that families want to assume the main role in the EI collaboration, they are also assumed to wish to be empowered with information and support to take on this role in its prescribed format. However when we look at the definition used in occupational therapy which describes empowerment as: “personal and social processes that transform visible and invisible relationships so that power is shared more equally” (Canadian Association of Occupational therapists [CAOT], 1997, p. 180) we can see the fundamental element in empowerment is undergoing a process of transformation. This entails a choice made consciously to start this process. In other words, to be truly empowered the parent needs to make the choice to do so freely, which will drive the process of transforming from passive recipient to an empowered and active partner in the collaboration. Now if we re-examine the perspectives of the parents in my study we see that they expect and want the therapist to lead the collaboration, a view which is shared by parents from western cultures within other studies (Franck and Callery, 2004, Kruijsen-Terpstra et al., 2016).

The responsibility placed on parents to assume an active role in the decision-making process, and later the implementation of the intervention was evident in the participants’ interviews who described feeling guilty when they couldn’t manage this demanding role on top of their daily family and work responsibilities (Parent role viewed as burden page number 128). This specific view is supported by the literature (Hanna and Rodger, 2002, Franck and Callery, 2004, Kruijsen-Terpstra et al., 2016) where professionals are advised to acknowledge the difficulties

parents face when they attempt to balance implementing home programmes with their other responsibilities. Health professionals are encouraged to be “intuitive listeners” when dealing with families of children with disabilities, and to avoid overwhelming parents with responsibilities by assuming they have the knowledge and time to be fully involved in the treatment (Rice and Lenihan, 2005).

In a study by MacKean et al. (2005) where the perspectives of 37 parents of children with developmental problems and 16 allied health professionals were collected, the main findings questioned the emphasis given to the role of parents to be responsible for their children’s care, by expecting them to take the lead in planning and implementing the treatment. Parents in this study described feeling overwhelmed with the responsibilities they are expected to handle, especially when they needed technical knowledge to be able to transfer information between specialists. This level of responsibility caused parents to feel guilt and worry that they might fail in giving specific information, or answering technical questions, which might cause harm to their children.

Similar findings resulted in my study, when parents described guilt feelings that were attributed to their inability to follow up at home because of their limited knowledge and expertise. Parents also referred to their busy daily life which impacted on their ability to implement the intervention as needed, thus they felt they were the reason the children did not achieve the aims of the intervention. There is a link here between assuming a partner role in the intervention, with its different responsibilities and expected participation level, and the perception parents have towards their own capabilities. In the studies by MacKean et al. 2005

(2005) and Kruijsen-Terpstra et al. (2016) as well as my study, parents expressed their worry and guilt towards their ability to assume a partner role in the intervention, they attributed this to: 1) their limited knowledge and experience referring to themselves as lay people in (Kruijsen-Terpstra et al., 2016), 2) the added responsibility of assuming this role when they already had their role as parents to worry about, and 3) their apprehension at not asking the right questions or making the correct decisions when needed (MacKean et al., 2005).

The negative feelings resulting from the parents' active participation brings into question the benefits of enforcing this partner role, especially when some families view this role as not wanted. Looking at the family needs and expected role is a first step in helping them assume the role they aim for. This is not the same as expecting the family to take on a full partner role in the intervention. In fact this expectation is shown to have caused unnecessary worry and guilt for the parents, which begs the question of how empowering it is to expect the family to take on a role seen by the therapists as the "correct" role? Wouldn't it be more empowering to support the family in identifying the most suitable role for them as a unique family?

The need to distinguish between families' needs which was evident in the findings of my study is echoed in the literature, with the call for professionals to adapt their roles according to the individual needs of the families (Kruijsen-Terpstra et al., 2016, Franck and Callery, 2004; Law et al., 2005; Rosenbaum et al. 1998), as the premises of the family centred practice rely heavily on the family position and role, highlighting the need to treat every family differently and as a unique unit, a term

referred to as ‘family individualism’ (Edwards et al., 2003) which is used to describe the uniqueness of each family, thus inviting therapists to consider each family as a unique entity, and attempting to assess their needs and strengths as one unit, however; this term needs to expand to include the preferred role which families want to assume in the intervention, one that is based on the priorities and various responsibilities which parents might have, and also derived from their cultural background. At the same time, practical applications of the family’s individuality needs to be studied in the literature, providing practicing EI professionals with strategies to implement the theoretical premises of FCM in their day to day work.

6.3.1.2. Elements of family centred model within EI in Jordan:

When studying the family centred early intervention programmes in Jordan several elements were discussed with the participants, either using direct questions or as part of the discussion, one element was home visits. With the parents group each participant was asked whether a home visit was conducted at any point in the intervention, the answer was always no. With the OT group they were asked whether they perceived home visits as important in the EI, and the answer was always yes but no home visits were done due to the organisational structure of the programme, however home programmes were used by all participants to support the parents’ training within the centre.

In a recent study by Malkawi et al. (in press) where 97 occupational therapists and physiotherapists specialised in EI completed a survey, their views on EI programmes in Jordan were collected, forming a general picture of such programmes for the first time. The results focused on the various elements of

family centred practice as typically used within EI, including: family involvement, home visits, home programmes, and age group served. The results describe variations in terms of how EI is presented in Jordan, with different settings being involved such as hospitals, rehabilitation centres, and even schools. This was linked to the age group served within the EI programmes which ranged from birth up to 6 years, which explains the involvement of school based rehabilitation in EI work. As for home programmes and visits, the study found acknowledgement from the therapists on the importance of involving family at home to follow up with the intervention, as 78% of the participants declared they did use home programmes, and when asked about the frequency of reviewing such programmes 40% of the participants said they did this once a month. These findings indicate a strong understanding of the importance of home programmes in the EI, which is backed up with an application of home programmes with the families. On the other hand home visits and particularly the use of the home environment for EI sessions and parent training were absent in this study by Malkawi et al (in press) similar to my study, as participants declared not conducting home visits due to restrictions within their organisations.

It is worth clarifying here that a common finding in the literature is the discrepancy between self-reports from occupational therapists on using home visits, and the actual practices observed via videotaping or through reports from parents, as therapists frequently report using home visits and a diversity of teaching techniques focused on teaching parents, while observations and reports from parents suggest a focus on hands-on interventions even during home visits, and

difficulty in learning from the therapists when active involvement of the parents is not utilised (Sawyer & Campbell 2012; .

The literature discusses the use of home programmes within paediatric occupational therapy in general and EI programmes extensively, as an essential element in the involvement of family and the use of family routine within intervention, as well as increasing the intensity of the therapy weekly and between intervention periods (Novak & Berry 2014; Milton et al. 2019; Colyvas et al. 2010).

6.3.2. **Parent-therapist collaboration seen through the cultural lens of Jordanian parents:**

The parents in my study discussed what makes one therapist better than the others. Their answers emphasised the emotional support some therapists could provide them, and when asked to describe these therapists, their answers revolved around communication, friendliness, listening, and humanistic caring attitude towards their children. When we look at the literature regarding positive attitudes of therapists within EI programmes described by parents, a similar overview is evident. MacKean et al (2005) surmised the importance of being honest in communication, seeking parents' input, listening, and being informative as traits in therapists. These descriptions resonate with both the relational and participatory help-giving practices which were first described by Trivette et al. (1996), as well as the emphasis given to respecting parents, listening to them, and believing them which are elements of the conceptual framework proposed by (Rosenbaum et al.

1998), all of which were supported later by studies looking into what promotes positive collaborations between therapists and families (King and Chiarello, 2014, Dodd et al., 2009; Law et al., 2005).

The perspectives of the parents in my study however moved further to describe supportive therapists as being *"like another family"*. The use of "family" to indicate closeness and comfortable interaction has its cultural significance here. In a collectivist culture such as the Jordanian one, which derives its understandings of family from social and religious concepts and emphasises of the group strength, the labelling of someone as being like another family means this person has gained trust and respect. In fact, this description moves the therapists from their status as a professional towards a closer level, which is interesting because the parents here are indirectly saying this 'good' therapist has been supportive in a way that a professional expert could not achieve. In other words, gaining the status of being "like family" means the therapist is no longer a stranger, and so it would be easier to collaborate and communicate with them away from the limitations of a professional communication.

This description emphasises the value of removing the 'image of expert' from the parent-therapist collaboration (Morrall, 2009). When the parents were treated without the professionally common image, such as formal meetings or professional distance, the collaboration was viewed as more beneficial by the parents. In other words; the power dynamics balanced when therapists approached parents in a non-professional manner, using friendly communication and utilising mannerism

similar to family interaction, where support is provided within a culturally acceptable form.

The impact of this description and its cultural significance might lead to a specific version of family centred models, which is possibly more appropriate to a collectivist culture. To achieve an active partnership with the family the therapist might need to move towards a less formal collaboration, in which their role moves away from the rigidness of professional collaboration, towards a friend or family like relationship. Thus may allow parents to open up to the therapist and become more expressive because they are less intimidated by the “expert”.

6.3.2.1. Family centred model use within Jordanian culture:

The cultural appropriateness of family centred models is unfortunately still not receiving much attention in the literature. According to Zwaigenbaum et al (2015) who identified in a literature review looking into studies about early intervention programmes for children, there is limited involvement of participants from diverse social and cultural backgrounds in current studies, a view that is shared by (Hanna and Rodger, 2002, Dodd et al., 2009, Kruijsen-Terpstra et al., 2016) who agree on the need to study the perspectives of culturally diverse families, in an attempt to identify possible variations based on the cultural backgrounds of families when it comes to their role in the EI.

My study looked specifically into the perspectives of Jordanian families who share Arabic and Muslim backgrounds, their views agreed with other families in the literature, but their pronounced emphasis on the ‘expert’ role of the therapists could be attributed to their cultural understanding of health professionals’ roles. In

a recent study by Malkawi et al (2020) looking into the influence of culture on the practice of occupational therapy in Jordan, the impact of the medical model within the Jordanian culture was evident, as 11 interviewed OTs agreed on their clients' preference to let the expert therapists take over the decision making process. This finding was attributed to the esteemed role of the expert in the Jordanian culture. Similarly, in a study by Al Busaidy et al (2012) where Omani occupational therapists were interviewed regarding the cultural significance of their work, participants discussed instances where parents of children with disabilities relied heavily on the therapists for guidance in the planning and implementation of treatment. This reliance was attributed to the Arabic culture which places health professionals on a high status in terms of knowledge, which requires a level of respect for the professionals' opinions.

A study by Yang et al (2006) which looked into the views of occupational therapists in Singapore regarding the cultural influence on their work revealed similar findings. Therapists discussed challenges they faced when attempting to encourage their clients and their families in the treatment. They described resistance that was attributed to the cultural understanding of the specialists' role in treatment, and the religious understanding of health and treatment, which influenced the clients' tendency to be involved or take a passive role in the intervention. This study identified an Islamic cultural influence as one of the reasons for the passive role clients might take.

6.3.2.2. Language use in parent-therapist collaboration:

Language in a professional interaction is viewed as one of the tools to potentially exert power or balance between the professional and the client, depending on how this language is used (Morrall, 2009). As professionals develop their own language with specific terminology and codes they are also developing a hierarchy where those who understand this language are amongst the 'expert' while others are not (Pollard and Sakellariou, 2012). An example of this is using the name of a diagnosis such as Cerebral Palsy between professionals, which immediately indicates a specific set of clinical signs and neurodevelopmental features that are understood by the professionals who had the opportunity to learn formally what this name means. But for the lay person who did not benefit from a medical or health related education the name Cerebral Palsy could mean nothing, or in some instances the word (palsy) could conjure a picture of paralysis, which is not in any way reflective of the image of CP. However, when professionals use this name CP in interactions between themselves or often with service users, they are in effect alienating the listener unless they belong to their 'expert' group.

Occupational therapy like any other profession has developed its own vocabulary, often using nouns with the prefix 'occupational' such as (occupational being, occupational justice, occupational balance) to describe specific understandings of phenomenon or acts, in an effort to acculturate students and professionals in an occupational therapy community, and thus construct shared meanings between occupational therapists around the world (Pollard and Sakellariou, 2012). However, this occupational therapy language has its foundations in Western English-speaking

culture which was the origin of the majority of occupational therapy philosophy and theories (Iwama, 2006), which resulted in limiting the meanings of core concepts to one language embedded in one cultural background. The impact of this is evident in non-Western OT educational programmes which are often taught in English even though the students are not native speakers of this language, forcing OT students in the majority of the world to attempt to understand core concepts in a foreign language, then try to communicate these concepts to service users (Pollard and Sakellariou, 2012). One example of this is the word 'Occupation' which is fundamental in the OT vocabulary, and refers to human engagement in doing, being, becoming, and belonging. But this very specific meaning can be confusing at best when the translation of this word into other languages can indicate a limited meaning (Iwama, 2006). In Arabic for example the word 'Occupation' means employment 'وظيفة' which translates the name of the profession of occupational therapy into Employment Therapy 'العلاج الوظيفي' in Jordan, and Vocational Therapy (العلاج المهني) in some Arabic countries (Darawsheh, 2018).

Jordanian occupational therapists reported this confusion in relation to the challenges they face to present their profession to the community, as the Arabic translation of the name itself is seen as a boundary, but also the different core concepts in OT such as autonomy and individuality which are in contrast to the cultural perspective within a collectivist culture such as Jordan. In fact Jordanian OTs reported struggles to promote interventions based on occupation to their clients because of the difficulty in relaying this complex concept to them (Malkawi et al. 2020). It is important to highlight here that the word (Occupation) has

different meanings in English language, the first one is “a person's usual or principal work or business, especially as a means of earning a living; vocation” (Dictionary, C. E. 2019) which suggest a potential confusion with clients even when their native language is English.

Reflection:

When she [Bayan] said (our profession is not clear) in the interview, I did not ask for clarification because I understood what she was talking about, it is a common complaint we OT have, people hear the name of our profession and don’t understand. But I should have asked her to clarify because her experience might be different than mine, my position as a Jordanian OT makes it difficult to avoid making assumptions.

In my study therapists referred to the ‘awareness of the community towards OT’ as one potential reason why parents do not engage actively in the sessions. Although their reference here might be related to the name of the profession itself, they might also have been talking about the core concepts of the profession such as autonomy, which was previously reported by Jordanian OTs (Malkawi et al. 2020; Darawsheh, 2018). Unfortunately; the therapists in my study did not clarify their meaning, this could be due to the fact that they were talking to another Jordanian occupational therapist, and thus felt the meaning was clear. On the other hand, I have not asked for clarification for this specific point because it was a shared

meaning we all had as occupational therapist from Jordan, that our profession is confusing to the community.

Occupational therapists around the world have to deal with such linguistic limitations of their profession's vocabulary when they interact with their clients, first by attempting to translate their professions' core concepts from English into their own language, then attempting to explain these concepts which are embedded in individualist philosophy into a collectivist understanding using spoken language, a struggle that is often documented in the literature (Pollard and Sakellariou, 2012, Iwama, 2006, Hammell, 2013). In the interviews with therapists I have noted their reference to the challenge in explaining their role to clients, they did not explain why there are facing this challenge but seemed to take this for granted. I reflected after one interview on my own experience with this struggle, and realised that it is a situation that was so common that it no longer required explaining. People do not understand what our profession is, this has become a fact we Jordanian OT simply accept.

The impact of using professional language (be it in English or translated into Arabic) in written and verbal communication with the parents was discussed in this chapter in relation to power dynamics within the parent-therapist collaboration. However, this is a barrier that could be perceived from the perspective of the therapist, to highlight a struggle they face in translating concepts they learned in English to their own language, a struggle which was discussed by different researchers in the field of occupational therapy (Hammell, 2013, Pollard and Sakellariou, 2012, Iwama, 2006). The therapists in my study discussed language as a barrier in relation to the

awareness of their role in EI stating that *"the problem is that our profession is not clear",* they described instances where they attempted to translate professional concepts to communicate better with the parents, however; they also revealed the lack of resources in Arabic language to use in communication.

The impact of using OT core concepts which are embedded in individualist philosophy goes beyond translating concepts from English to another language, it is shown in the struggles of the therapists; who have been trained and ultimately acculturated to adopt ideologies prizing autonomy and individuality, when working with clients esteeming community responsibility and interdependence (Hammell, 2019). The effect is reflected in resistance from clients to the efforts of the therapists to engage them in OT interventions, as these efforts do not 'fit' with the clients' needs. This struggle is crystallised in a gap between what the therapists have learned and accepted as their role, and the day to day interactions with their clients which results in their frustration with unsatisfactory results.

Through the interviews I had with Jordanian OT they did not question their professions' core concepts, they did question their own efforts, and they expressed frustration with their clients responses to their efforts to promote parent engagement. At the same time parents expressed guilt at not having adhered to the therapists' directions, guilt at not gaining the anticipated positive results from the EI programme. While the frustration of the therapists and the guilt of the parents are potentially the results of unbalanced parent-therapist collaboration; as discussed earlier in this chapter; we cannot ignore the impact of attempting to use models and core concepts that do not seem to fit with the Jordanian culture, a

situation where the efforts of individual therapists to find a compromise between their own cultural understandings and those of their profession cannot change the dominant neoliberal ideology prevailing in the OT profession.

7. Chapter Seven: Summary and conclusion

7.1. Summary:

Family centred care has existed since the 1990s, with an emphasis given to the role of the parents as experts of their child (Hanna and Rodger, 2002, Case-Smith and O'Brien, 2014, Zwaigenbaum et al., 2015). However, there is a limited application of family centred care within occupational therapy, and reported challenges to parents partnership in Early intervention (Smith et al., 2015, Novak and Honan, 2019, Zwaigenbaum et al., 2015). Parent partnership within occupational therapy interventions is found to be one of the best evidence-supported interventions according to the literature (Novak and Honan, 2019), however; parents report their need for information related to their children's conditions, and access to supportive services. Parents also report resistance from health professionals in general to their partnership role, emphasising the unrealistic expectations they face which causes them stress (Coyne, 2015).

In my study I have looked at the parent-therapist collaboration within EI from the perspectives of both parents and occupational therapists, and used observations and EI record reviews to form an understanding of the contextual impacts on this collaboration. This study is taken purely from the perspectives of Jordanian individuals within a non-Western culture, which provides a unique perspective on the cultural impact on using family centred model within EI (Zwaigenbaum et al., 2015).

The findings from my study describe the complexity of forming and maintaining parent-therapist collaboration with contextual and cultural factors impacting directly on this process. Both parents and therapists described a situation where they are attempting to find a compromise between what they need and what is expected from them. At the same time this complex collaboration formed around the power dynamic that places the therapist as the expert in this relationship, and limits the role of parents to recipients or assistants to the therapists. I have reviewed instances where this power dynamic was evident through the language used or the actions of the therapists, as well as the contextual factors which encouraged the expert power, including the policy and organisational structure of the EI programme.

My findings also suggest that another factor impacts the parent-therapist collaboration which is the occidental philosophy of occupational therapy, evident in the Westernised core concepts and underlying assumptions which Jordanian occupational therapists reported struggling to explain to the parents. This underlying challenge impacted the manner in which therapists explained their own profession, and consequently reflected on the understanding of the OT role within the parent-therapist collaboration. The hegemonic impact of Western based philosophy on occupational therapy core concepts and theories was reflected in a role dissonance experienced by participating therapists, who commented on their struggle to implement the role they have anticipated per their education, while the reality of their work demanded an expert role as it would fit with the culturally accepted role of the therapist in Jordan.

The findings in this thesis suggest that the unbalanced power within parent-therapist collaboration observed in this study is a symptom of different problems at several levels: 1) organisational structure and policies within the EI programmes in Jordan, 2) a gap between the OT educational programmes and the reality of OT work in Jordan and other Non-Western countries, 3) limitations in the family centred models and occupational therapy core concepts in terms of cultural sensitivity, and 4) paucity in the work generated from Non-Western scholars to lead the de-colonisation of occupational science and occupational therapy philosophy.

7.2. Conclusion:

7.2.1. **A new family centred model:**

The findings from this study provided a picture of the formation and progression of family-therapist collaboration within one EI programme in Jordan, a process that revealed how power dynamics within a therapeutic relationship could impact the engagement of clients, and possibly reflect on the therapists' satisfaction with their own role. While the main findings agree with the available literature in terms of the factors affecting parent's active engagement in the intervention, and the difficulty in implementing the family centred model from the perspectives of therapists and parents, the participants in this study provided a unique view of how their Eastern culture impacted their expectations from the EI programme, and thus influenced the parent-therapist collaboration.

This culturally specific perspective which was not previously represented within the available literature highlighted the need for more culturally sensitive family centred models, a view that is shared by several authors (Hanna and Rodger, 2002, Kruijsen-Terpstra et al., 2016, Dodd et al., 2009, MacKean et al., 2005). While the current version of the family centred model takes into account the individual needs of the family, by looking at their communication style and priorities, there is a need to adopt this version of the family centred model to highlight the importance of viewing families according to their individualistic needs and cultural backgrounds, at the same time ensuring families are given the power to decide on the role they will assume within the EI programme, rather than being prompted to assume a role prescribed within the family centred model which may or may not meet their needs.

At the same time it is important to bridge the gap between the theoretical elements of the family centred model, and the actual application of these elements within paediatric settings especially early intervention programmes. This can be best done by producing more research on the strategies therapists use within EI, as well as their struggles to implement culturally sensitive family centred models. And such studies need to also consider the perspectives of diverse therapists and family clients from non-Western cultures, to further develop a diverse practice and a multitude of practical strategies to fit different cultures.

The participating occupational therapists in the study presented their strategies in dealing with the limitations of the family centred model, by using their own skills to accept family needs, and adapting their collaboration to meet these needs.

However; their efforts were greatly dependant on their personal skills, and was not supported within the family centred model, which resulted in negative feelings of frustration and guilt. At the same time, parents interviewed in this study revealed their own struggles with the use of family centred model in early intervention programmes, and provided examples of variations in family needs which were not always met or accepted.

This picture of family centred model early intervention programmes in Jordan might not be generalizable due to the small sample, but it is valuable in understanding different views of both parents and therapists within an Eastern culture, and thus providing us with a starting point to shift our thinking towards developing a more flexible a family centred model to fit different client groups within various cultural backgrounds. This study supports the need for more research taken from the perspectives of non-Western clients and therapists, their views of occupational therapy work and specifically parent-therapist collaboration would provide the literature with a much needed perspective, to develop a more diverse and culturally sensitive models of practice. Research in this area could be a starting point to de-colonise occupational therapy and occupational science theories and philosophy, as we begin listening to the voices of clients and therapists from around the world.

7.3. Clinical implications:

In this study I observed the impact of constructing and carefully encouraging a positive collaboration between parents and therapists in EI, and the importance of

this collaboration which is reflected on the success of the EI programme (Hanna and Rodger, 2002, Rodger and Kennedy-Behr, 2017). When parents and therapists have a balanced collaboration they are more likely to work together to achieve better results both at the early intervention centre and at home. But this collaboration is a complex process that begins at the first meeting between parents and therapists, and develops gradually over time. Thus, to understand this collaboration we need to look at its elements. In my study, the power scale framework emerged from the findings and this illustrates the elements of parent-therapist collaboration; knowledge, expectation, and engagement. These three elements are presented for each party (parent and therapist) starting at the beginning of the intervention and developing through the process of building the collaboration.

When parent and therapist meet for the first time they both are coming with their own set of knowledge and expectations, at this point a discussion to reveal these expectations and the underlying knowledge is necessary to achieve common ground, where shared expectations are formed, and gaps in knowledge are filled. This initial discussion could also help reveal the individuality of this family, through exploring their needs as a unit, and clarifying cultural assumptions and understandings. With this step achieved both parents and therapists can assume their roles in the collaboration.

However; while this process in theory seems simple, this research also illuminated the various needs of parents, which is reflected in the literature as the individuality of families. Parents expressed different needs when they discussed early

intervention and their expected role. While some wanted the therapist to take charge and tell them what to do, others wanted to be active partners and have an actual role in making decisions, and one parent even wanted to have the power to change the system of the early intervention programme to meet the needs of the parents, a role that indicated a need to be part of the designing process of the programme as a whole, or even an advocate role in terms of the rights and need of parents and children.

These variations in needs of the parents introduces another level of complexity to the process of building and developing a collaboration between parents and therapists, the challenge of revealing these needs would require advanced skills from the therapists in terms of interviewing and using their selves therapeutically, because often parents themselves are not clear about their needs at the start of the EI programme, and would need an ongoing open discussion of what they want from the team, and what level of participation they anticipate for themselves.

At the same time, we need to look critically at the elements of family centred model which push for one level of participation from the parents, that is being an active partner. However; as revealed in this study supporting findings represented previously by other researchers (Zwaigenbaum et al., 2015), this prescribed role is not suitable for every family, and perhaps those who wish to follow the directions of the experts are in fact choosing the type of role which is more suitable to their family needs and their personal abilities. Thus, the current version of family centred model needs to allow for these variations, and to re-examine the concept of empowering parents. Empowerment is currently described as a role where the

parent oversees making decision and directing the team, but another version of empowerment where the parents defines their role per their needs maybe more applicable, even if this choice is to let the therapist make decisions because they have trust in their professional expertise.

The resulting power scale framework in this study might have an impact on the work of therapists within early intervention programmes, if utilised at the start of the parent-therapist collaboration therapists can achieve a shared expectation with the parents, and plan activities to fill knowledge gaps tailored to the needs of the parents, this framework will also help therapists understand what the parents want and need from the programme, which would impact the roles taken by the parents and therapists in the intervention.

On the other hand, when therapists examine their own knowledge and expectations from the early intervention programme, they can anticipate professional development needs and thus put an effort into developing their professional skill. This step could be taken in collaboration with their managers who could develop a clear understanding of the advanced skills and knowledge necessary for therapists working in EI, which would be used to develop training activities and potential collaboration with educational programmes in local universities.

7.4. Strengths of the research:

This study provides a unique perspective on using family centred model within early intervention programme, unlike the majority of studies in this topic which are

taken from the point of view of western therapists and clients (Zwaigenbaum et al., 2015). My study looked into the parent-therapist collaboration by interviewing Jordanian occupational therapists and parents, as well as observing sessions within a Jordanian EI programme. This non-Western perspective helps reveal how the family centred model which is derived from Western philosophy is being used within an Eastern culture, and the findings helped in highlighting the limitations of the family centred model when challenged with culturally different contexts.

The use of multiple sources of data including interviews with therapists and parents, review of records, and observations of different therapy sessions provided this study with a comprehensive picture of the factors impacting the formation and development of parent-therapist collaboration. Both parents' and therapists' perspectives were valuable in describing how this collaboration is formed and developed, and also what is working or not working from their different points of view. This description revealed the various expectations from the parent-therapist collaboration, and the nature of this collaboration with its power dynamics which were described differently from the two participating groups. On the other hand, the observations and review of records gave a concrete description of the nature of this collaboration, and supplied the foundation for what was later asked in the interviews.

The use of constructivist grounded theory as a methodology, in which reality is viewed as a constructed process between the researcher and participants, provided a good fit with the phenomenon being studied which is the parent-therapist collaboration. As a form of relationship that is constructed between

parents and therapists, this collaboration was deconstructed using the perspectives of both parties, and then supported with contextual observations to form an understanding of how this relationship (or phenomena) is constructed naturally within this specific cultural and political contexts. At the same time, the iterative nature of grounded theory, in which constant comparison is used to collect data then move to analysis and back again depending on where the data is leading, supported the use of multiple data sources where the findings from the first phase of data collection helped in formulating the questions in the second phase interviews, then the initial findings from both phases directed the literature review. This helped in grounding the findings in the data collected, and describing themes that voiced what the participants said, and what was observed.

Currently, research in the field of occupational therapy in Jordan is very limited, and there are no studies related to early intervention or the occupational therapy role within it. This has an impact on the development of the occupational therapy profession as a whole in Jordan, as indicated from a study in the field of physiotherapy on the needs of children with cerebral palsy by Almasri (2014), which concluded the urgent need to provide early intervention services for children, and to provide parents with a much needed support. While research in the fields of occupational therapy and early intervention is limited, the need to investigate the perspectives of parents and therapists constitutes an urgent requirement to the development of service standards, and a comprehensive strategy to improve rehabilitation services in Jordan, not to mention the positive

impact this research might have on the academic curricula within universities related to rehabilitation professional education.

This study emerged from observations and questions which were derived from my experience working within an early intervention programme in Jordan. During my practice the need to understand how parent-therapist collaboration is developed became essential, with more observations of how different families required different strategies to promote their role. The importance of studies which are based on clinical work is highlighted throughout the occupational therapy literature, with an emphasis on utilising clinical practice to formulate research questions.

The use of clinical experience moved beyond establishing the aims of this study, to the choice of research methodology in order to enable the understanding of perspectives of parents and therapists at the same time. Furthermore; as an experienced occupational therapist in Jordan I have developed extensive connections within the field of rehabilitation, which facilitated communication with early intervention programmes, and provided access to occupational therapists within the field of paediatrics.

During data collection, my position as an early intervention therapist allowed me to conduct interviews with an understanding of the topic, as well as an insider role rather than the typical position of researcher which is seen as an outsider to the participants' area. This position helped me in establishing rapport with the two participant groups either as a colleague or a therapist, which allowed them to open up in their discussion and for me to relate to their experiences. At the same time,

during the observations and review of records my experience as an early intervention therapist assisted me with a contextual knowledge of how the sessions and records are organised, which helped me focus on observing and note taking efficiently and with minimum interruption to these sessions.

7.5. Limitations:

Being a therapist was strength while collecting data, but it formed a challenge when two of the occupational therapists who were interviewed recalled my previous role as their clinical supervisor during their clinical training. This challenge was clear when they referred to my experience and asked for my opinion following my observations of sessions. My position as a researcher was emphasised to the participants, but I could not help reflecting on the participants' comments and wondering whether their views were coloured with this previous relationship.

It was also challenging for me as an occupational therapist to refrain from giving technical advice during the interviews with the parents, especially when the parents discussed issues with the technical decisions, and asked me for my opinion as a therapist. I have maintained throughout the data collection a reflective journal to help in ensuring an awareness of this change in the role between researcher and therapist. I also took time after every interview to direct the parents to resources available for them.

7.5.1. **Data collection:**

One of the main limitations identified is related to the recruitment process. With unclear statistics of the number of EI occupational therapists working in Jordan, as well as the rather vague definition used for EI centres within the governmental agencies and policies (HCD, 2019), it was challenging to reach EI occupational therapists. In an attempt to spread the word and reach as many therapists as possible the Jordanian Society for Occupational therapists was approached. They used their social platforms to post the announcement for recruitment in this research, and many therapists shared this announcement. The respondents to this announcement were only 14 in total, with 9 responding through the advertisement and 5 were referred later by participants. After initial contact it became clear that 6 of them did not actually work within an EI programme, but worked in a general paediatrics centre that offered services to younger children. Due to this only 7 were approached to participate in the data collection, and unfortunately two were too busy to participate.

The planned activity to collect data from participating occupational therapists was initially a focus group, which aimed to record the views within a discussion between therapists with different experiences, with the hope of using the conversation to encourage an in-depth discussion of the EI programmes in Jordan. Unfortunately, only two participants showed up for the planned focus group, and following this only three more agreed to be interviewed. This caused a problem as the number of participants in the OT interviews was only 5 therapists, and the planned focus group did not happen.

It is however important to highlight the general situation of early intervention programmes in Jordan. After reviewing the policies and researching the two main government bodies in charge of rehabilitation programmes in Jordan, it became clear that the term (Early Intervention) is used vaguely as a description for programmes. On the Higher Council for Persons with Disabilities HCD website (HCD, 2019) which is the main organisation which monitors the quality of services related to rehabilitation in Jordan, there is a document that details the registered centred and programmes in the country, and the main area of practice with the available services. In this document a total of 288 centres around the country provide paediatric rehabilitation services, of those only 28 centres are declared to include an EI programme and occupational therapy services, however only three centres were in the geographical area of Amman and had a clear EI process that is documented in the records. When contacting those three centres only one has agreed to the data collection process, while the other two refused to allow access to the records or observations of sessions.

Due to this limited number of centres who actually apply the principles of EI programmes and have records of the intervention process, the data collection process was limited to only one centre. This is a limitation as the findings of the study only provide an understanding of the organisational context of this centre. It is important to point out here that this study attempted to gain the perspective of occupational therapists in other centres as well, and thus did include three participants who worked at different centres to at least gain their perspectives regardless of the organisational policies in place.

The context of EI programmes in Jordan which includes policies and laws at the government level was researched prior to the start of the second phase of data collection phase. The aim was to derive some questions regarding the general application of EI principles in the country when interviewing parents and therapists. However; when reviewing the laws it was clear that the term EI was used mainly for educational programmes targeting children from the age of 2 year to 6 years. This clarified the confusion regarding the availability of EI programmes in Jordan, and the expertise of OT, since the laws are not clear regarding the criteria of EI programmes, it is only natural for centres to be unclear regarding their services, which would impact the type of experience the therapists gain while working at those centres.

To clarify these laws and policies the HCD was contacted to gain access to a research study which was done in the 2016. The report of this study was available online (HCD, 2019) and a review of it is included in the first chapter of this thesis, also; the Higher council for the affairs of persons with disabilities is currently conducting a second study to evaluate the early intervention programmes in Jordan, but the findings from this study are not available for the public yet.

7.6. Recommendations:

One of the central findings in this study was the power imbalance evidenced within the EI programme, this overarching theme was described from the perspectives of parents and therapists but in different ways. While parents discussed their expectations and reliance on the ‘expert’ knowledge of the therapists, they also

discussed emotions of guilt that resulted from their perceived 'lack of adherence' and with some parents the sense of being alienated when they challenged the authority of the therapists. On the other hand, therapists discussed the role of parents by categorising parents into groups based on their initial expectations and later their engagement, which was evaluated according to how the parents continued the intervention at home, an evaluation that at its core puts the therapists as the leaders of the intervention.

The proposed framework (power scale) which was discussed in chapter 5 is a theoretical overview of how power dynamics within a therapeutic relationship could shift to the therapists, or even out depending on the interaction between the three elements Knowledge, Expectations, and Engagement. My study concluded the factors impacting power dynamic within the parent-therapist collaboration could be summarised into:

1) Organisational structure and policies within the EI programmes in Jordan.

2) A gap between the OT educational programmes and the reality of OT work in Jordan and other Non-Western countries.

3) Limitations in the family centred models and occupational therapy core concepts in terms of cultural sensitivity.

4) Paucity in the research work generated from Non-Western scholars to lead the de-colonisation of occupational science and occupational therapy philosophy.

Thus, the recommendations of my study could be divided into three main points:

7.6.1. **Organisational structure of EI programmes in Jordan:**

It is important for the organisational structures in Jordan responsible for designing policies and monitoring their applications to empower clients and their families. This empowerment includes involving them in the design process, and then maintaining open channels with them to hear their voices as a representation of how they experienced these services. At the same time health professionals need to be included in the design and monitoring processes, as there is a limited evidence-base foundation for the government to use in updating policies. The health professionals have a valuable source of data to provide, and through their involvement the reality of how services operated could be reflected, as well as identifying their strategies and efforts to adapt their work to suit the Jordanian culture.

The Higher Council for persons with Disabilities in Jordan is in charge of monitoring the quality of services within rehabilitation centres, and has conducted one study in 2016 to review EI programmes in Jordan (HCD, 2019). In the introduction chapter I discussed this study in detail. It helped in providing a general overview of the programmes available in terms of number of staff and facilities available, however; there were no examination of the design of the programmes or the use of family centred practice. This constitutes the approach used for monitoring quality of EI services in Jordan, as the number of staff and a description of the physical facilities seems to represent the criteria for quality of services. While parents' and staff perspectives are not studied or represented as a quality assurance criteria or a factor in the design of policies.

On the other hand; each centre has its own policies in relation to staff responsibilities and parents' role. In my study I have given examples of the EI contract which was reviewed in the EI records, this contract detailed the role of the parents and emphasised their adherence to the directions of the therapists. My study provides an example of how the policies of the EI programme could have an impact on the power dynamics within parent-therapist collaboration, and by reviewing these policies to reflect a family centred model we can change the foundation of EI programmes, which would reflect in an organisational structure that promoted parents' involvement and potentially their empowerment.

As part of my study I took steps to disseminate the findings with the hope of making an impact on the EI programme where this study took place, through my request for approval to collect data within the EI programme I have offered to give a report of the findings, without using any identifying data, and propose recommendations to improve the EI programme. The management of the EI programme welcomed this offer and requested I prepare an educational package with up-to-date information regarding early intervention programmes and parent-therapist collaboration, so that the EI team will use this information to support their learning and parents' coaching.

At the level of policy making, I presented the findings from my study in the 4th International Conference on Community Based Rehabilitation in Jordan on the 8th of December 2018, an opportunity that gave me an opening to present my findings to representatives from the Jordanian government including the Higher Council for persons with Disabilities and the Ministry of Health, as well as representatives from

non-governmental organisations, local universities, and Jordanian researchers in the fields of rehabilitation and special education. My presentation focused on the findings from this study, with recommendations related to future collaboration between researchers and the local organisations. My study was received with positive feedback and resulted in different collaborations with a local non-governmental organisation, two universities, and one private training centre, all looking to provide advanced training for therapists in the field of early intervention and parent-therapist collaboration.

It is essential for policy makers in Jordan to utilise available and future research to set up standards for EI programmes in the country. These standards can direct such programmes to be more family centred while maintaining culturally sensitive systems. On the other hand, my study illuminated challenges that the therapists face when attempting to include parents in the goal setting process. This can be facilitated at the regulations level if collaborative goal setting standards are adopted and used within OT setting in general, especially EI programmes.

7.6.2. **Occupational therapy profession in Jordan:**

Therapeutic use of self is one of the main skills practiced by occupational therapists, one that is essential within educational programmes because of its core role in facilitating client-centred practice and collaborative therapeutic relationships in practice. Thus; therapists are ideally equipped with knowledge and skills to help them collaborate with their clients, and help them take their role at the centre of the intervention. However, these skills are still not being utilised

within family centred practices in paediatric settings (Dodd et al., 2009, Hanna and Rodger, 2002, King and Chiarello, 2014, Rodger and Kennedy-Behr, 2017) which is one of the main challenges facing the implementation of family centred practice. One of the reasons for this is the continued reliance on the "expert role" which is observed in practicing therapists, who report ethical dilemmas and difficulties in sharing authority with the families.

This leads us to the main recommendation for occupational therapy in Jordan; **promoting empowerment as an essential role of occupational therapists**. This has been advocated for within the profession's literature not only in paediatrics but all through the different practice areas where therapists work. Unfortunately, this role remains unclear due to the reported difficulties therapists face including contextual factors, such as policies and regulations within their organisations, and the advanced training required to take on an empowering role within practice (Rodger and Kennedy-Behr, 2017, Bamm and Rosenbaum, 2008, Hanna and Rodger, 2002). The Jordan Society of Occupational Therapy JSOT which is the professional body representing occupational therapists in Jordan has a fundamental role in shaping the role of therapists, with its access to most therapists and universities in Jordan, as well as its connection with the World Federation of Occupational Therapists WFOT. JSOT have the opportunity to set up practice standards for the professions, and provide advice for educational programmes in the field to promote these standards. The JSOT could also provide therapists with advanced training on the skills required to promote empowerment of clients, which would in turn assist therapists in taking on this role within the various settings in Jordan.

There is, however; a responsibility on the individual therapist to become aware of their perception of their own role; a reflection on how they might perceive themselves as 'experts' or as supporters of their clients. This reflection is the first step in assuming an empowering role with clients, as therapists become aware of the language they use in front of their clients, the practices they use to help promote an active role of the client, or the attitudes they have when faced with disagreements or challenges from their clients. Becoming aware will help the therapists seek further training to help them when they need in this difficult role, it will also facilitate communications with clients around this topic which in itself is an empowering step, and finally this awareness will gradually build a culture between therapists revolving around this role.

The responsibilities of therapists also include their advanced knowledge of how to identify and adhere to family needs, which is achieved by looking at the family's individuality in terms of their daily routine needs, social and financial requirements, cultural background, and other responsibilities that might impact the families' ability to assume their role in intervention. This kind of skill is complex and required advanced training related to interviewing skills, cultural competency, and using family centred practice to work with the family as a unit, not merely as a support system for the child.

7.6.3. **De-colonising Occupational therapy research:**

The findings from my study emphasised the need to consider the cultural sensitivity of family centred models, and the often called for actions within the OT literature

to re-evaluate our profession's core concepts and philosophical underpinnings, and move towards a culturally neutral profession. The perspectives of Jordanian parents and occupational therapists captured in my study indicate a challenge that is influencing OT work, when western-based theories and models are being used in Jordan, and the struggles therapists face to fit core concepts with their and the clients' cultural background.

The literature discussed here has supported these perspectives, although the paucity of research to reflect the needs of non-western clients and therapists was acknowledged (Dodd et al., 2009, Zwaigenbaum et al., 2015). This requires a movement within the research community in occupational therapy towards studying the needs of non-western clients, and to represent the views of non-western therapists within the OT profession. This movement will help in providing the profession with the tools to re-evaluate its core concepts, and change the often criticised theories and models to meet the needs of clients around the world.

The beginning is thus, with the research community, which have the opportunity to give voice to clients and therapists around the world, then provide the profession with potential ways to support diverse needs. The impact of this movement will reflect on occupational therapy practice all around the world, as clients from immigrant communities and diverse cultural background are being supported within western communities more and more due to migration related to political and environmental crisis. It is becoming more urgent now to dedicate efforts within the research community for the purpose of filling the gap and representing non-

western cultures, by incorperating core concepts in the occupational therapy profession that are reflective of non-western cultures too.

The findings from my study were presented at different research events in the UK and Europe to give voice to Jordanian occupational therapists, in the hope that a non-western based research in occupational therapy would help in shedding some light at the need to de-colonise our profession. I have presented my study within the annual Royal College of Occupational Therapists conference RCOT 2018, which had a specialist section focused on children, young people, and families. My presentation resonated with several therapists who worked with clients from Middle-Eastern backgrounds, and commented on the challenges they face daily, which they found to be reflected in my findings.

In June 2019 I have participated in the OSE Occupational Science Europe conference in Amsterdam. My participation was in the pre-conference group where I presented a short overview of my study and the findings within the (empowerment group). The pre-conference groups focused on discussing various topics that have an impact on occupational science, then give feedback and recommendations to the pre-conference meeting of the International Social Transformation through Occupation Network.

At the university level, I have presented two posters in the Health and Social Care HSC school annual staff-student research conference in the years 2016 and 2017, then presented my study at the HSC research seminar in 2018, followed by a presentation of the findings within the 2018 HSC school annual staff-student research conference. My presentations in these events provided me with various

feedback from the staff and students within my school, which assisted me in my research and provided me with an outsider perspective to provide comments on the study.

7.7. Future research:

This study helped in giving an understanding of the parent-therapist collaboration within early intervention, however it also pointed to the areas that require more investigation. The participating therapists referred to their education and the idealistic family centred model they have learned about as one of the main impacts on their work, but this area requires further study. This would include looking into the occupational therapy curricula in Jordanian universities, and interviewing educators and practice educators, in order to clarify how occupational therapy educational programmes prepare future therapists to work with parents within the Jordanian culture.

On the other hand, parent-therapist collaboration is a specific form of therapeutic relationship, which develops not only within an occupational therapy context but also within other health professions, thus, further research on the perspectives of allied health professionals in Jordan who work in early intervention would provide a valuable source.

This study was limited to one early intervention programme, which means there is an opportunity to study different programmes and compare the needs of parents and therapists with my study. The value of looking into different programme will reflect on the policy and regulations in Jordan regarding early intervention

programmes, as a comprehensive examination of parents' and therapists' perspectives might provide a basis for a change in policies or potentially the formation of an adapted family centred model that is suitable within the Jordanian context.

Finally, while qualitative research has provided an in-depth study of parent-therapist collaboration, we do need to look into developing outcome measures that can be used in quantitative research to provide a picture of the parent-therapist collaboration within paediatric settings. This will support evidence based practice in this area, and provide the research body in Jordan with various studies to enrich the professions, which will reflect in the future on educational programmes in occupational therapy and consequently on clinical settings.

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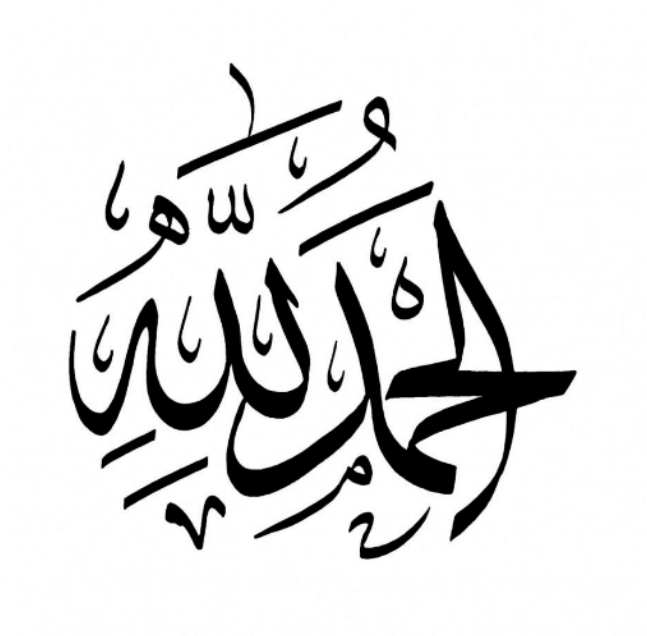


Praise be to Allah

Appendix 1: Participant consent form

CONSENT FORM

Study title: Family centred Early intervention programmes in Jordan: a grounded theory study into family and occupational therapists' collaboration

Researcher name: Nisrin Alqatarneh

Please tick the box(es) if you agree with the statement(s):

I have read and understood the information sheet and have had the opportunity to ask questions about the study.	☐
I agree to take part in this research project, and agree for my data to be used for the purpose of this study.	☐
I agree to have my interview audio recorded.	☐
I understand that my participation is voluntary and I may withdraw at any time without my legal rights being affected.	☐
If I choose to withdraw from this research I allow the researcher to use my data unless I inform her otherwise.	☐
I understand my personal details such as phone number and address will not be revealed to people outside the project.	☐

Data Protection

I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study. All files containing any personal data will be made anonymous.

Name of participant (print name)……

Signature of participant……..

Date……

Appendix 2: Participant information sheet – Parents

Participant Information Sheet (Parent)

Study Title: **Family centred Early Intervention programmes in Jordan: a grounded theory study into family and occupational therapists' collaboration**

Researcher: Nisrin Alqatarneh

Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

This research is a student project and will be presented as the thesis for my PhD programme (in Occupational therapy) which I am doing now at the University of Essex. As an Occupational Therapist who worked in a paediatrics setting in Jordan for 10 years, I have become interested in studying the factors affecting therapist-family collaboration within the paediatric occupational therapy programmes, especially within Early Intervention programmes. This research will examine the strategies used by Jordanian occupational therapists to build and facilitate a positive cooperation between them and the families of children who receive early intervention. It will also study the views of the families regarding their role within the Early Intervention programme, and how they are encouraged to be part of the intervention.

Why have I been chosen?

This study will include two different groups of participants; 1) the families of children who received Early Intervention, and 2) Jordanian occupational therapists with an experience working in early intervention.

As a parent of a child who receives or have received Early Intervention in the past 6 months you could provide us with your valued perspective on your role within the intervention.

What will happen to me if I take part?

As a participant you will be interviewed one time by the researcher, the interview will take place in a location agreed upon with you, the duration of the interview is estimated to be no more than two hours and it will be in Arabic.

Are there any benefits in my taking part?

There may be no direct benefits to you, but the results of this study will possibly produce recommendations that will benefit occupational therapy as a profession in Jordan, as well as early intervention programmes, which may in turn improve the services provided for your child within these programmes.

Are there any risks involved?

There are no risks predicted for you, your participation is limited to providing your opinion and perceptions. Any statements you provide regarding your child or your experience with the early intervention programmes will be confidential and will not be accessed by anyone other than the researcher. When reporting these views later in publications your pseudonym will be used, and any details that might hint to your identity will be removed.

Will my participation be confidential?

You will be asked to choose a pseudonym which will replace your name on any documents in the study, and will be used within the thesis and possible publications in the future. All references related to the professional positions of the participants will not be enclosed. The World Federation for Occupational Therapy WFOT Code of Ethics will be adopted during this study, as well as the Data Protection Act 1998/University policy, the research procedures will provide you with anonymity as all the interview transcriptions and recordings will be accessed only by the researcher. All data will be saved in a password protected computer accessed only by the researcher.

What happens if I change my mind?

You have the right to withdraw at any time from this research without any effects on your legal rights. The data collected from you will be used in the study unless you choose to exclude it, and will remain stored with the study documents.

What happens if something goes wrong?

If you feel at any time that you wish to complain or comment on any event related to this research, then you can contact the Al Hussein Society (AHS) using the following contact information:
Tel: (+962) 6 581 7599
Email: info@ahsrehab.org

Dr. Wendy Bryant

Tel: +44 (0)1206 872282
Email: wbryant@essex.ac.uk

Dr. Mark Francis-Wright

Tel: +44 (0)1206 874408
Email: mfrancis@essex.ac.uk

Where can I get more information?

If you require any information related to this study please do not hesitate to contact the researcher on the following details:

Nisrin Alqatarneh

Mobile: (+962) 77 7202822
Email: nsmalq@essex.ac.uk

Study Title: Family centred Early intervention programmes in Jordan: a grounded theory study into family and occupational therapists' collaboration

Researcher: Nisrin Alqatarneh

Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

This research is a student project and will be presented as the thesis for my PhD programme (in Occupational therapy) which I am doing now at the University of
Essex. As an Occupational Therapist who worked in a paediatrics setting in Jordan for 10 years, I have become interested in studying the factors affecting therapist family collaboration within the paediatric occupational therapy programmes, especially within Early Intervention programmes. This research will examine the strategies used by Jordanian occupational therapists to build and facilitate a positive cooperation between them and the families of children who receive early intervention. It will also study the views of the families regarding their role within the Early Intervention programme, and how they are encouraged to be part of the intervention.

Why have I been chosen?

This study will include two different groups of participants; the families of children who received Early intervention, and Jordanian Occupational therapists with an experience working in Early intervention.
As a Jordanian Occupational therapist with an experience working within an Early intervention program, you can provide us with your perspective on how the therapist family collaboration is formed and improved throughout the intervention.

What will happen to me if I take part?

You will participate in a focus group with other occupational therapists, where a discussion regarding the topic of the research will be encouraged; your views within the focus group will help this study in providing a picture of what the therapists think and how they deal with their collaboration with the families.

Are there any benefits in my taking part?

There may be no direct benefits to you, but the results of this study will possibly produce recommendations that will benefit occupational therapy as a profession in
Jordan, as well as early intervention programmes.

Are there any risks involved?

There are no risks predicted for you, your participation is limited to providing your opinion and perceptions. Any statements you provide regarding your work or your experience will be confidential and will not be accessed by anyone other than the researcher.

Will my participation be confidential?

You will be asked to choose a pseudonym which will replace your name on any documents in the study, and will be used within the thesis and possible publications in the future, all references related to the professional positions of the participants will not be enclosed. The World Federation for Occupational Therapy WFOT Code of
Ethics will be adopted during this study. As well as the Data Protection Act 1998/University policy, the research procedures will provide you with anonymity as all the focus group transcriptions and recordings will be accessed only by the researcher. All data will be saved in a password protected computer accessed only by the researcher.

What happens if I change my mind?

You have the right to withdraw at any time from this research without any effects on your legal rights. The data collected from you will be used in the study unless you choose to exclude it, and will remain stored with the study documents.

What happens if something goes wrong?

If you feel at any time that you wish to complain or comment on any event related to this research, then you can contact the supervisors of this study at the University of
Essex using the following contact information:

Dr. Wendy Bryant

Tel: +44 (0)1206 872282
Email: wbryant@essex.ac.uk

Dr. Mark Francis-Wright

Tel: +44 (0)1206 874408
Email: mfrancis@essex.ac.uk

Where can I get more information?

If you require any information related to this study please do not hesitate to contact the researcher on the following details:

Nisrin Alqatarneh
Mobile: (+962) 77 7202822
Email: nsmalq@essex.ac.uk

Appendix 3: Observation framework

Observations

Date:

Session type:

The environment (physical and people):

The role of the therapist:

The role of the parent:

Appendix 4: Interview guide – Occupational therapists

Interview guide Occupational Therapist:

Do you think EI is known in Jordan? By doctors? By families? By OT?

Was family centred model discussed in you OT education?

Did you learn about the EI at the university?

How would you describe the role of the parents in the EI programme?

What do you think of the assessment process within EI?

In your opinion, what should be the role of the family in the assessment?

Are parents involved in the planning of the intervention?

How do you identify the parents' priorities within EI?

In your experience, how do parents respond to the session schedule?

How would you describe the role of parents within the sessions?

What do you think your role as a therapist is within the session?

In your experience do families follow up home?

If given the opportunity and resources what would you do to improve the EI programme?

Which would you think more suitable in Jordan the home-based EI or clinic-based?

Appendix 5: Interview guide - parents

Interview guide
Parents

General information:

How old is your child?
What is his/her diagnosis?
How long have you been coming to this programme?

1. How did you hear about the Early Intervention programme?
2. Did your child go to a similar programme before?
3. In your opinion what is the goal of the EI programme?
4. Can you describe to me your overall experience in the EI programme?
5. What do you think your role is within this programme?
6. Describe to me a day routine when your child has a session here?
7. Did you have a family-team meeting here? What was the aim of it?
8. During a session for your child what is your role?
9. Do you have a home programme to follow with your child?
10. What does this home programme include?
11. Have you had a chance to look at your child's file in the EI?
12. When your child started the programme the team did an evaluation for him/her, can you describe how this evaluation was done?
13. Are you familiar with the EI plan for your child?
14. Did you participate in the planning of the intervention for your child?
15. Did the EI team describe the situation of your child to you?
16. Can you describe the nature of the collaboration between you and the EI team?
17. Do you have any suggestions to improve this collaboration?
18. Do you think the therapist is in charge of your child's therapy? ***

Appendix 6: Ethics approval from the Ministry of Health in Jordan

Translation for the Jordanian ethical approval document:

CODE: MOH REC 160103

Research ethical approval committee

The research ethical committee at the Ministry of Health have met in 18th July 2016 to discuss the application form presented by:

Nisrin Soud Alqatarneh, a PhD student

Entitled:

Family centred Early Intervention programmes in Jordan: a grounded theory study into family and occupational therapists' collaboration

And the committee has approved this application and grants ethical approval for the research

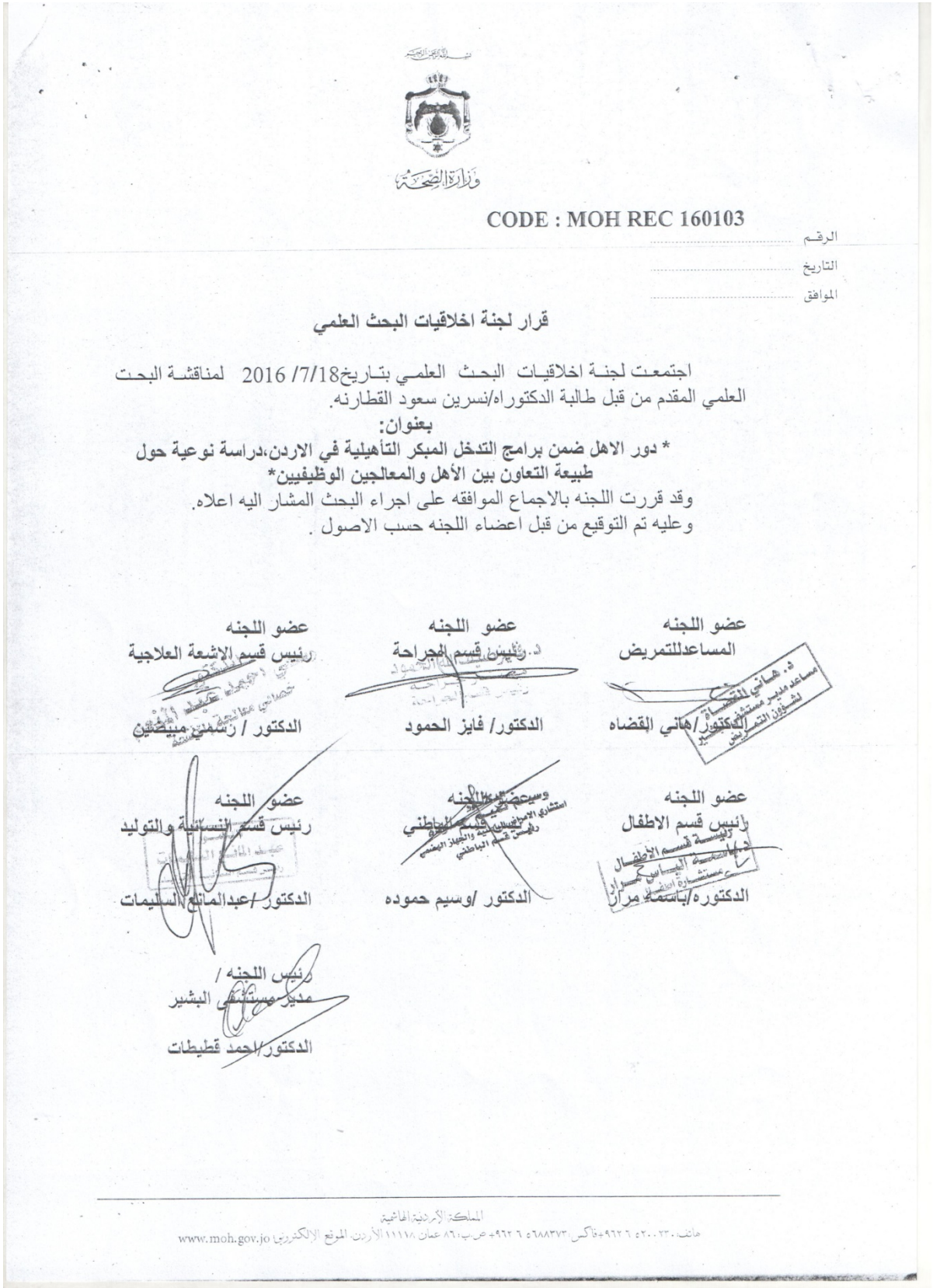
Signatures of the committee members:

www.moh.gov.jo

Tel: +962 6 5200230 Fax: +962 6 5688373 P.O box: 86 Amman 11118 Jordan

The original Ethical approval from the Ministry of Health in Jordan:

The original Ethical approval from the Ministry of Health in Jordan:



وزارة الصحة

CODE : MOH REC 160103

الرقم .....
التاريخ .....
الموافق .....

قرار لجنة اخلاقيات البحث العلمي

اجتمعت لجنة اخلاقيات البحث العلمي بتاريخ2016 /7/18 لمناقشة البحث العلمي المقدم من قبل طالبة الدكتوراه/نسرين سعود القطارنه.

بعنوان:

*** دور الاهل ضمن برامج التدخل المبكر التأهيلية في الاردن،دراسة نوعية حول طبيعة التعاون بين الأهل والمعالجين الوظيفيين***

وقد قررت اللجنه بالاجماع الموافقه على اجراء البحث المشار اليه اعلاه.

وعليه تم التوقيع من قبل اعضاء اللجنه حسب الاصول .

عضو اللجنه	عضو اللجنه	عضو اللجنه
المساعدللتمريض	رئيس قسم الجراحة	رئيس قسم الاشعة العلاجية
الدكتور/هاني القضاه	الدكتور/ فايز الحمود	الدكتور / رشمي مبيضين
عضو اللجنه	عضو اللجنه	عضو اللجنه
رئيس قسم الاطفال	رئيس قسم الباطني	رئيس قسم النسائية والتوليد
الدكتوره/باسمه مراد	الدكتور /وسيم حموده	الدكتور /عبدالمانع السليمات

رئيس اللجنه /
مدير مستشفى البشير
الدكتور/احمد قطيطات

University of Essex

Appendix 7: University of Essex Ethics approval

06 October 2016

MISS N. ALQATARNEH
SAINTY QUAY
SQ/H5/12/0
UNIVERSITY QUAYS
LIGHTSHIP WAY
COLCHESTER
ESSEX
CO2 8GY

Dear Nisrin,

Re: Ethical Approval Application (Ref 15050)

Further to your application for ethical approval, please find enclosed a copy of your application which has now been approved by the School Ethics Representative on behalf of the Faculty Ethics Committee.

Yours sincerely,

Lisa McKee
Ethics Administrator
School of Health and Human Sciences

cc. Research Governance and Planning Manager, REO
Supervisor

Colchester Campus
Wivenhoe Park
Colchester CO4 3SQ
United Kingdom

School of Health and Human Sciences
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Appendix 8: Example for the analysis process – line by line coding

Parent describe his role as: attend sessions, train on exercises, follow up at home. / feeling guilt for not having time or energy to follow up at home. the blame is placed on parents for not doing home exercises. what about OT role to include training as part of daily routine? Isn't the therapists for giving extra work at home? Blame on therapists for giving extra work at home?

Interview: 2

27-7-2017

	this will continue for the first or second or third classes and so on		
	And how can you describe your role within this?	N	
- agreeing & EI main aim (integration) - describing challenges parents face. - showing signs of guilt for not having time at home to follow up - attending sessions despite challenge of work & time training at sessions	we are very involved in this aim, we want her to be ready by the time she starts her first grade, even if at least she could walk, so our only obstacle now is that me and my wife we both work, so we go home every day and we are exhausted, we have no energy to talk or to do anything else, and we try to encourage her to use the walker at home, and I do some exercises, but we are not doing what we should, we go home tired and can't do all the exercises, so we are participating, whenever there is a session I do come here and learn, even though I should be at work, but I would manage and take some hours off work so I could come here and participate in the sessions, so I can follow up at home, and my wife whenever she could manage a day off she would also attend sessions here	T	Guilt for not doing home prog. * role of parent: train in session attend + follow up at home * challenges of following at home bc of work
	And when you are in the session, do they teach you what to do at home?	N	
- receiving info & home programme - noticing progress in all areas. - describing training in OT session - hiring a maid to assist in home int.	yes, they did explain everything, in all the different areas, they would give us papers and instructions to do at home, like the speech, and I noticed that my daughter did progress really well in all the different areas, so the occupational therapist would show me the exercise and tell me that this is for her right arm and then she would teach me how to do stretching exercise and ask me to do the exercise in front of her, and she would check up, and at one point we also had a maid who would come with us here, so they also taught her how to handle my daughter and what exercises she needs to do at home.	T	- training in session - process of training - using extra help.
	Did they give a home programme? A written one or recorded videos so you wouldn't forget what they did in the session?	N	
- using video recording to document training in session	no, they didn't give me written or video, but my wife did record using her phone some exercises, but she did this on her own, I even recorded sometimes while my daughter was walking, but the team never asked us to record or gave us recording	T	EI providing training but no documentation writing or video.
	You said you and your wife both work, and the sessions here	N	

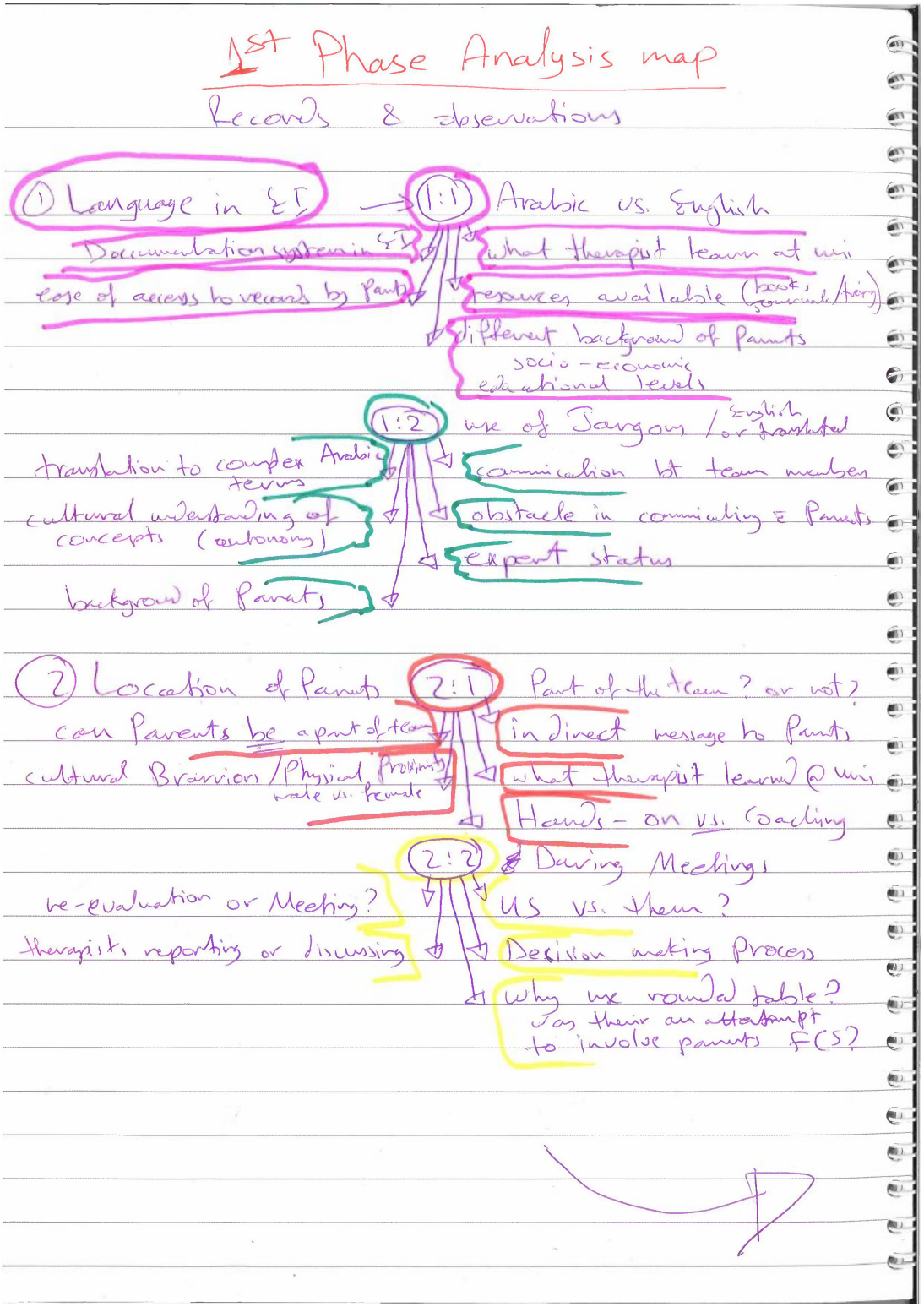
Appendix 9: Analysis process 1st phase – codes to categories

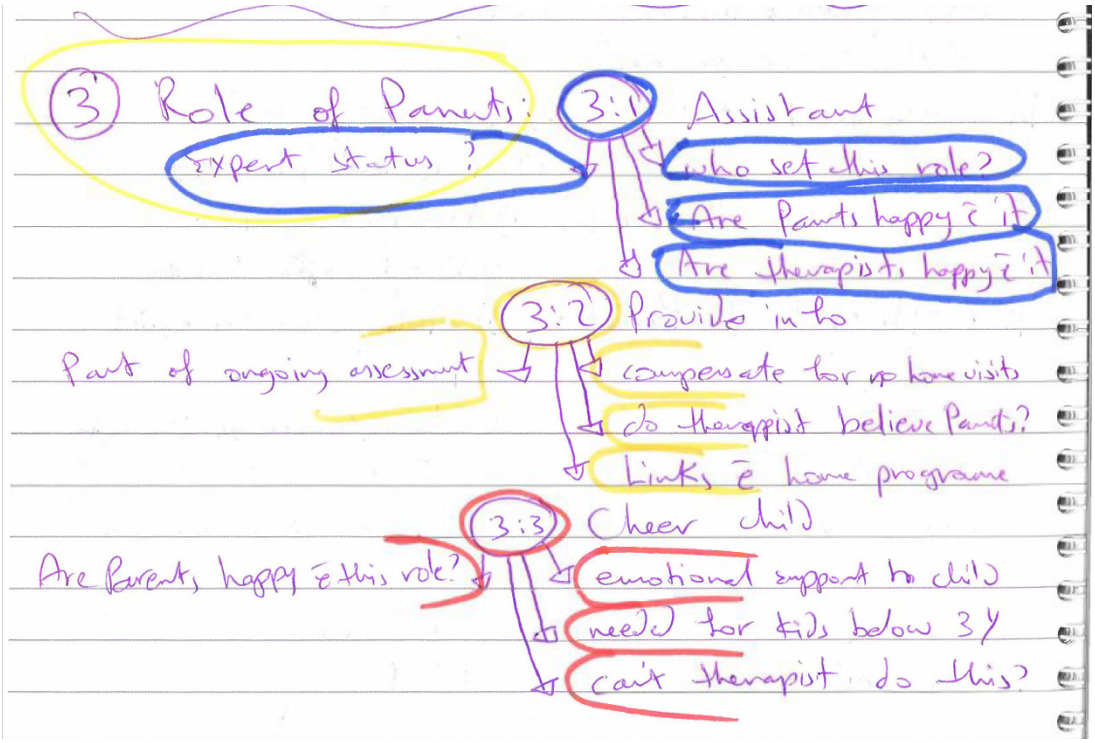
1st Phase Observations:

Code	Family code	Category	Data type
Sitting on a mat	Parent location during session	Included or excluded	OT session
Sitting at the back of the room			OT session
Sitting away from child			OT session
Giving comments	Informant	Parent's role in session	OT session
Encouraging child	Cheer the child		OT session
Commenting on his role	Seeking information		OT session
Directing child to focus	Cheer the child		OT session
Working directly with child	Hands on therapy	Observed OT role within session	OT session
Prompting child physically	Hands on therapy		OT session
Encouraging child verbally	Verbal encouragement		OT session
Talking to child	Verbal encouragement		OT session
Asking father for information about child at home	Seeking information		OT session
Explaining child performance	Giving information		OT session
Explaining child struggle	Giving information		OT session
Sitting around table	Round table	location	Parent-team meeting
Using a private room	Room choice		Parent-team meeting
OT explaining the aim of the meeting	Giving information	OT role in meeting	Parent-team meeting
Describing the OT goals	Setting goals		Parent-team meeting
Explaining child progress	Giving information		Parent-team meeting
Discussing child main problems	Collaborating with parent		Parent-team meeting
Explaining how team deals with problems	Giving information		Parent-team meeting
Giving home programme comments	Giving information		Parent-team meeting
Using "behavioural modification" as term	Jargon used	Professional language and terminology	Parent-team meeting
OT Giving an example to clarify in Arabic	Using Arabic language		Parent-team meeting

Mother not understanding	Lost in translation		Parent-team meeting
Using translated terms	Jargon used		Parent-team meeting
Asking for explanations	Seeking information	Mother role in meeting	Parent-team meeting
Seeking more information	Seeking information		Parent-team meeting
Giving general goals and priorities	Informant		Parent-team meeting
Using large room	Room choice	Location and setting	Assessment session
mother and child sitting on mat	Included or excluded		Assessment session
Mother sitting behind child	Included or excluded		Assessment session
EI team sitting around child	Included or excluded		Assessment session
Explaining to mother the goal	Setting the goal	EI team role	Assessment session
Interacting with mother	Giving information		Assessment session
Using A&S questionnaire	Asking questions		Assessment session
Asking child to play with toys	Hands on therapy		Assessment session
Asking mother about child at home	Asking questions		Assessment session
Giving the mother the decided number of sessions	Giving information		Assessment session
Explaining to mother findings in Arabic	Using Arabic Language	Lost in translation	Assessment session
Discussing child performance in English	Using English		Assessment session
Asking team about EI	Seeking information	Mother role	Assessment session
Explaining previous experiences with other programmes	Giving information		Assessment session
Answering team questions	Giving information		Assessment session
Prompting child to focus	Cheering child		Assessment session
Volunteering information	Giving information		Assessment session

Appendix 10: 1st phase analysis process - categories to themes




3 Role of Parents
expert status ?
3:1 Assistant
who set this role?
Are Parents happy ē it
Are therapists happy ē it
3:2 Provide info
Part of ongoing assessment
compensate for no home visits
Do therapist believe Parents?
Links ē home programme
3:3 Cheer child
Are Parents happy ē this role?
emotional support to child
need for kids below 3 y
can't therapist do this?

Appendix 11: Transcript with coding and reflective memos - OT

* OT P.O.V on the start of OT-parent rapport; if they have no time to build a foundation for the collaboration how can they encourage parents to be active?

2 Interview: OT [redacted] 30-7-2017

building rapport & child & parents not possible	the team, you know we don't at that stage have developed a rapport with the child or parents, it should be a time for us to play with a child and talk with the parents just get them comfortable, so it is very difficult to do a proper evaluation!	* imp. of the establishment of the collaboration & parents.
	N: so what do you do? how do you actually evaluate the child	
trying to make the best of an assessment session using first two OT session to do an assesment explaing to parents the imp of rapport & assesment setting goals & parents trying to get over difficulties in the EI system setting ~~not~~ sessions	M: for me I personally use this session, that is what we got, so i bring toys and try to play with the child and through this play I look for some things, also I ask the mother a lot of questions, and then I just get a general idea, but on our first OT session I tell the parents that I need to do an in-depth assessment so I take the first two sessions for that, I like to build a good relationship with the child, so that they wouldn't be scared of me, so I tell the parents that, and I explain that I will use the first session or two to build a rapport and assess their child, I also use these two sessions to set the goals with the parents. but you know in the evaluation session we need to decide on the number of sessions that the child will need weekly, sometimes I can decide from just one session, but if I realize late that I need more session I still can adjust the schedule, so there is some flexibility	* how OT deals & a difficult EI system.
	N: ok good, I'm interested in the stage when you set the goals with the parents, can you explain it to me?	
explaing what OT is to new parents giving examples of goals or setting them for parents & start parents giving the difficulties they face which become goals asking parents for info on difficulties	M: well at this stage I find parents would want to know about OT, you know what we do, what does OT mean, how can I help the child, most parents ask this, so I explain to them, you see I have to give them examples and sometimes even set the goals myself, but when we start talking and they realise what I focus on I find they start to give some goals of their own, like (yes my child can't hold the milk bottle) so they start to give me the difficulties they face at home, and that is great, so I keep asking them to give me their comments and then explain that those kind of difficulties will be the base for our goals, and I think that is a way	* setting goals & new parents * give example * set them herself * problem solving to set goals * using difficulties to set goals * strategy to promote cooperation

* how OT prompts parents to be active, by explaining & giving examples of goals, even setting the first ones themselves, then use the problems they have as a base for OT goals
good strategy !!

Appendix 12: Analysis process – from codes to categories

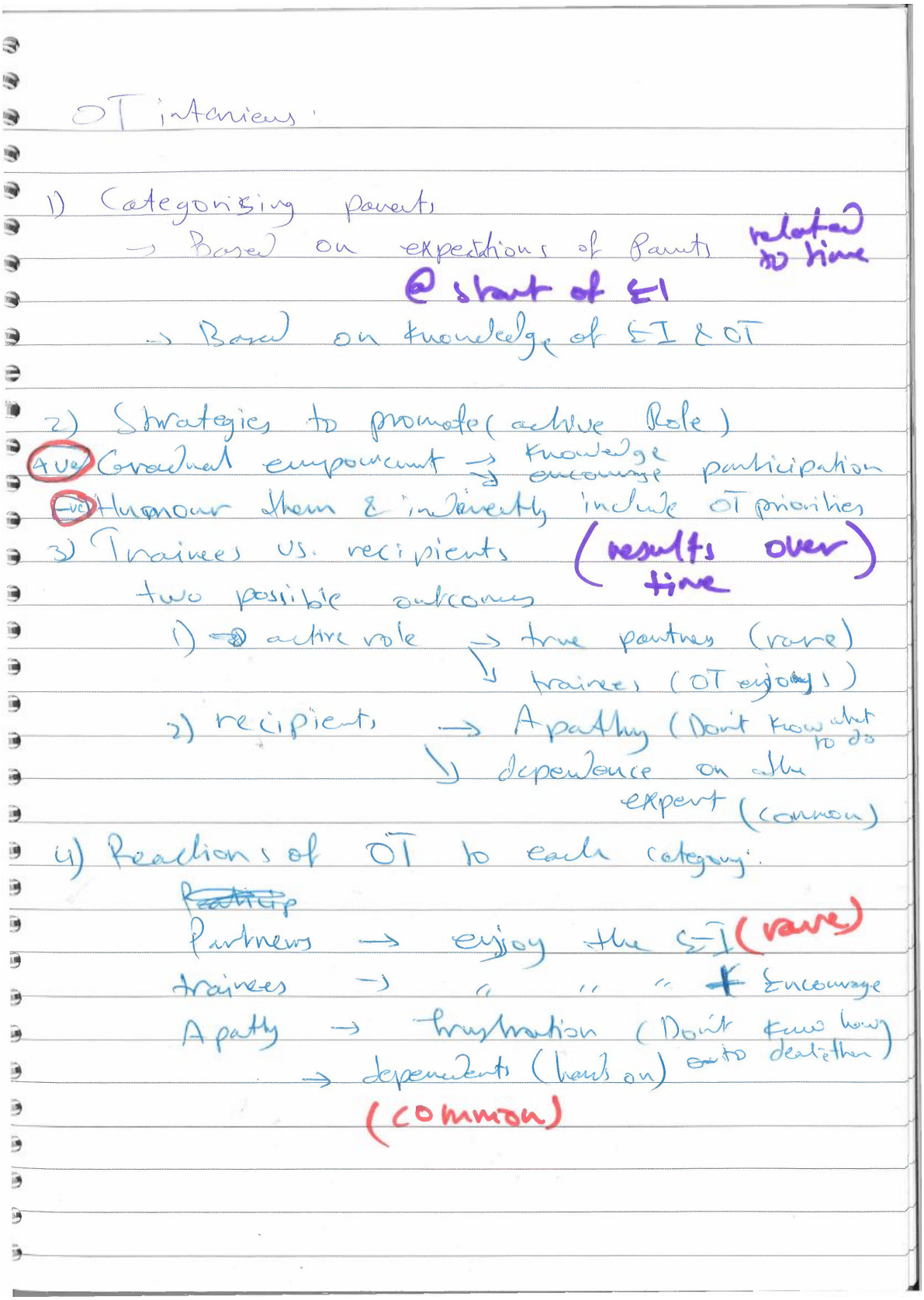
2nd phase: Parent interviews

Code	Family code	Category
Searching for rehabilitation services	Identifying the need for EI	Awareness of EI in the community
Facing confusion with different services	Identifying the need for EI	
Being advised child is too young for rehabilitation	Challenging the need for EI	
Using the internet to search for programmes	Choosing EI programme	Referral to EI
Looking at different centres		
Hearing about EI from family/friend	Hearing about EI	
Being referred to EI by a therapist		
Visiting the EI programme	Choosing EI programme	Process of choosing EI programme
Assessing the child on the first day	Assessment process	Assessment at EI
Staff explaining the purpose of assessment	Receiving information from EI staff	Information from EI
Observing the staff during assessment	Parent role in assessment	Role of parent in session
Answering questions about the child		
Prioritising physiotherapy	Setting goals	Goal setting process
Focusing on motor development	Setting goals	
Setting goals with the team depends on the therapist	Setting goals	
Talking to physiotherapist about the goals	Setting goals	
Involving parent in OT by telling them the goals	Setting goals	
Focusing on the parent priority	Prioritising parent goals	
Agreeing with the team's goals	Adhering to team goals	
Facing challenges at home	Challenges faced by parents	Follow up at home
Showing signs of guilt for not finding the time to follow up	Feeling guilty	Emotions due to EI process
Feeling unhappy with the staff	Feeling unhappy	

Describing EI as extreme pressure	Feeling stressed	
Attending session as required	Parent role in sessions	Role of parent in session
Using video recordings to remember exercises in sessions	Solving problems by parents	Active role of parent
Trying to influence the centre policy to solve challenges	Taking an active role in EI	
Suggesting changes to EI procedures	Taking an active role in EI	
Adjusting the work schedule to fit with EI sessions	Making suggestions	
Presenting the suggestion to the centre management	Taking an active role in EI	
Facing challenges at work to take time to attend sessions	Challenges faced by parents	Parents' struggles
Thinking of the integration of the child into school after EI	Challenges faced by parents	
Describing a confrontation with the EI team	Being challenged by team	Team response to parent active role
Facing rejections from the team	Facing rejection from team	
Facing criticism from team	Facing rejection from team	
Being treated differently by the team	Being punished by EI team	
Feeling punished by the team	Being punished by EI team	
Describing role as recipient of services	Parent role	Parent role as recipient
Changing attitude to become passive with the EI	Becoming passive	
Helping therapist by comforting child	Helping OT in the session	Parent role as trainee
Training by the OT on different exercises	Training on intervention activities	Parent role as trainee
Receiving verbal comments from therapist	Verbal comments from therapist	Parent role as trainee
Traveling to centre every session	Describing struggles	Parents' struggles
Dealing with changes to session schedule	Feeling stresses	
Describing challenges at home	Describing struggles	
Suggesting to EI staff to change the session schedule	Making suggestions	Active role of parent
Missing sessions due to travel time	Describing struggles	Parents' struggles
Asking questions about child	Seeking information	Parent role

diagnosis		
Getting information when OT discusses child with students	Collecting information indirectly	Parent role
Missing training at programme due to home issues	Describing struggles to participate in EI	Parents' struggles
Feeling happy about the EI	Happy about EI	Perception of EI
"she knows better than me"	Perceived parent role	Expert role
Referring to the OT experience	"I don't interfere in these things"	Expert role
Preferring OT with experience	Describing criteria for best therapist	Choice for therapist
Asking for male physiotherapist	Describing criteria for best therapist	
Preferring therapist who is good with child	Describing criteria for best therapist	
Feeling EI team are like family	Close relationship to therapists	"they are like family"
Receiving emotional support	Supportive therapist	
Receiving sessions at home will solve traveling issue	Preferring home based EI	Home-based EI

Appendix 13 Second phase OT- from categories to themes



OT interviews:

1) Categorising parents
   → Based on expectations of parents (related to time @ start of EI)
   → Based on knowledge of EI & OT

2) Strategies to promote (active Role)
   (+ve) Gradual empowerment → knowledge encourage participation
   (-ve) Humour them & indirectly include OT priorities

3) Trainees vs. recipients (results over time)
   two possible outcomes
   1) active role → true partners (rare)
      → trainees (OT enjoys)
   2) recipients → Apathy (Don't know what to do)
      → dependence on the expert (common)

4) Reactions of OT to each category:
   ~~Participate~~
   Partners → enjoy the EI (rare)
   trainees → " " " + Encourage
   Apathy → frustration (Don't know how to deal with)
   → dependents (hands on) (common)

types of parents

OT: → ① They don't know about SI or OT, they expect OT to take child & do session, they don't want to be involved / ~~[illegible]~~

② ~~They~~ resist insist on (walking, speech) as goals & reject OT goals

② They need / heard about SI (internet, others, abroad) they want to be part of the int. they ask, train, follow inst.

③ they are lost, they don't even know their priorities, maybe had bad experiences, very passive

Appendix 14: Second phase findings parents' interviews- categories into themes

initial

2nd phase findings:

* Focus of parents is on PT (Motor-walking)
* confusion as to where to seek rehab for child below 3 yrs.
  - -> Doctors views & recommendations
  - -> using the internet (Rehab in other countries)
  - -> advice from people
  - -> Private sessions @ home

(6) awareness of EI in community

* Priorities of Parents:
  - * Motor accomplishments -> walking
  - * Speech

(1) why? OT profile

* Knowledge of OT from EI team
  - -> limited to ADL independence + handwriting & perception
* involvement in goalsetting of EI intervention:
  - -> expectation: to be told / informed of goals
  - -> focus on Motor / speech (Parent priority)
  - -> Reality: accept other priorities bcoz EI know what is best for child

(2) expert

* Role of Parent:
  - -> attend sessions @ EI
  - -> train or exercise
  - -> follow up @ home
  - -> Cheer child during sessions => observation
  - -> answer Qs from EI => observation

(3) Parent role? trainee

* Guilt for :
  - → not starting EI early
  - → not being able to follow up @ home
  - → focusing on Motor only

(4) blaming parents for not achieving to home EI

* Challenges to follow up @ home :
  - → Parent's work
  - → other children
  - → no time to apply recommendations of EI
  - → seek assistance (maid @ home / change caregiver)

but is it really their fault ??

* communication @ EI :
  - → access to file & int. plan
  - → home programme (written, video ---)
  - → discussing progress of child (3 months Parent-re-evaluation & team meeting)
  - → scheduling of sessions ?? / vs. Meeting

access to file

* Parent's involvement in policy making & adjusting system:
  - → suggestion by parents (@ are rejected by EI (not their business to suggest)
  - → reaction to this suggestion = (stepping on EI authority)

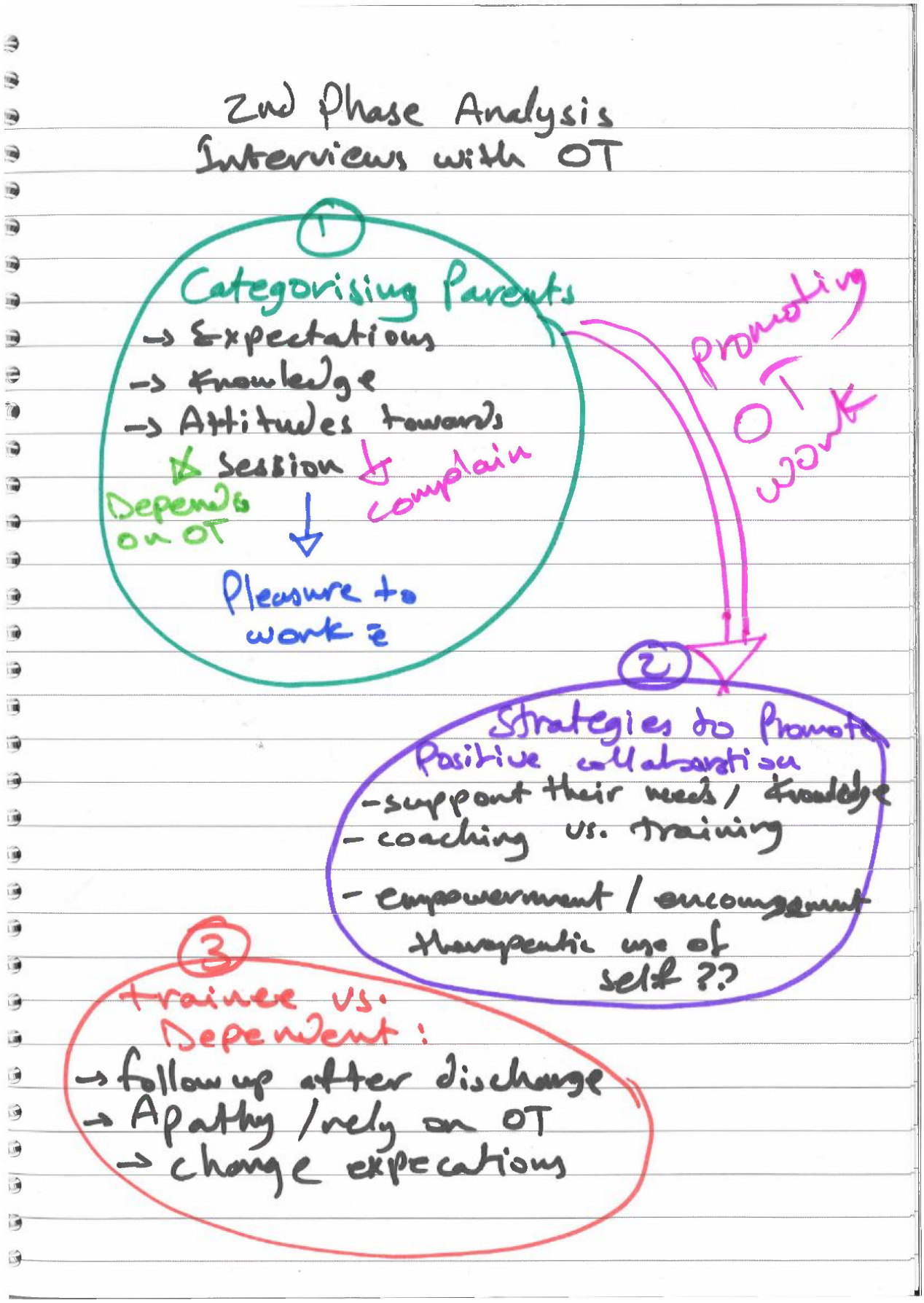
* Suggest with specific techniques

(5) Parent role

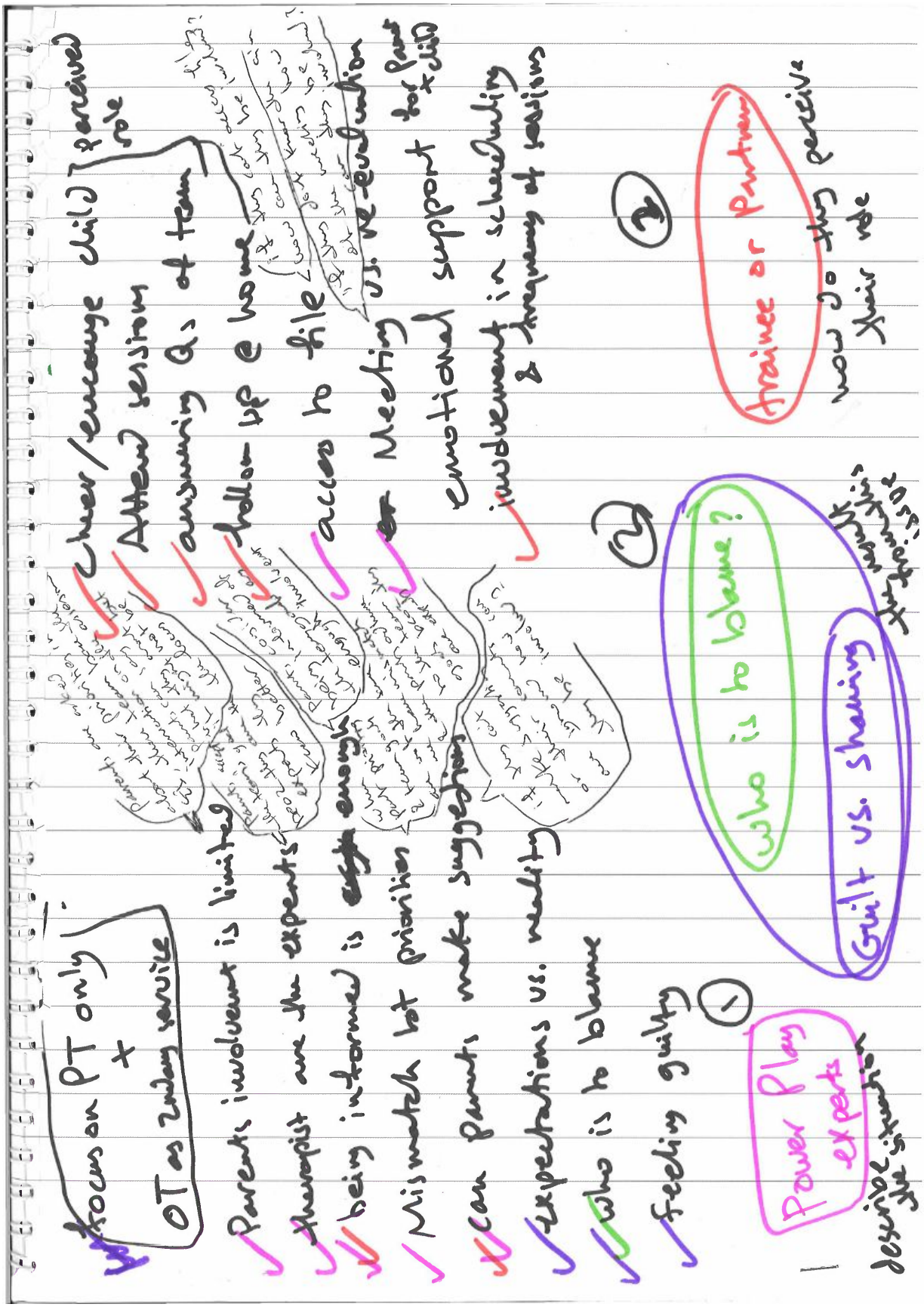
Partner advocate decision-maker

  - → change treatment to parents / penalizing ??
  - → what makes parents' role as Partner? P.O.V of parents
* EI @ as home based vs. centre based
  - → cultural
  - → socio-economic

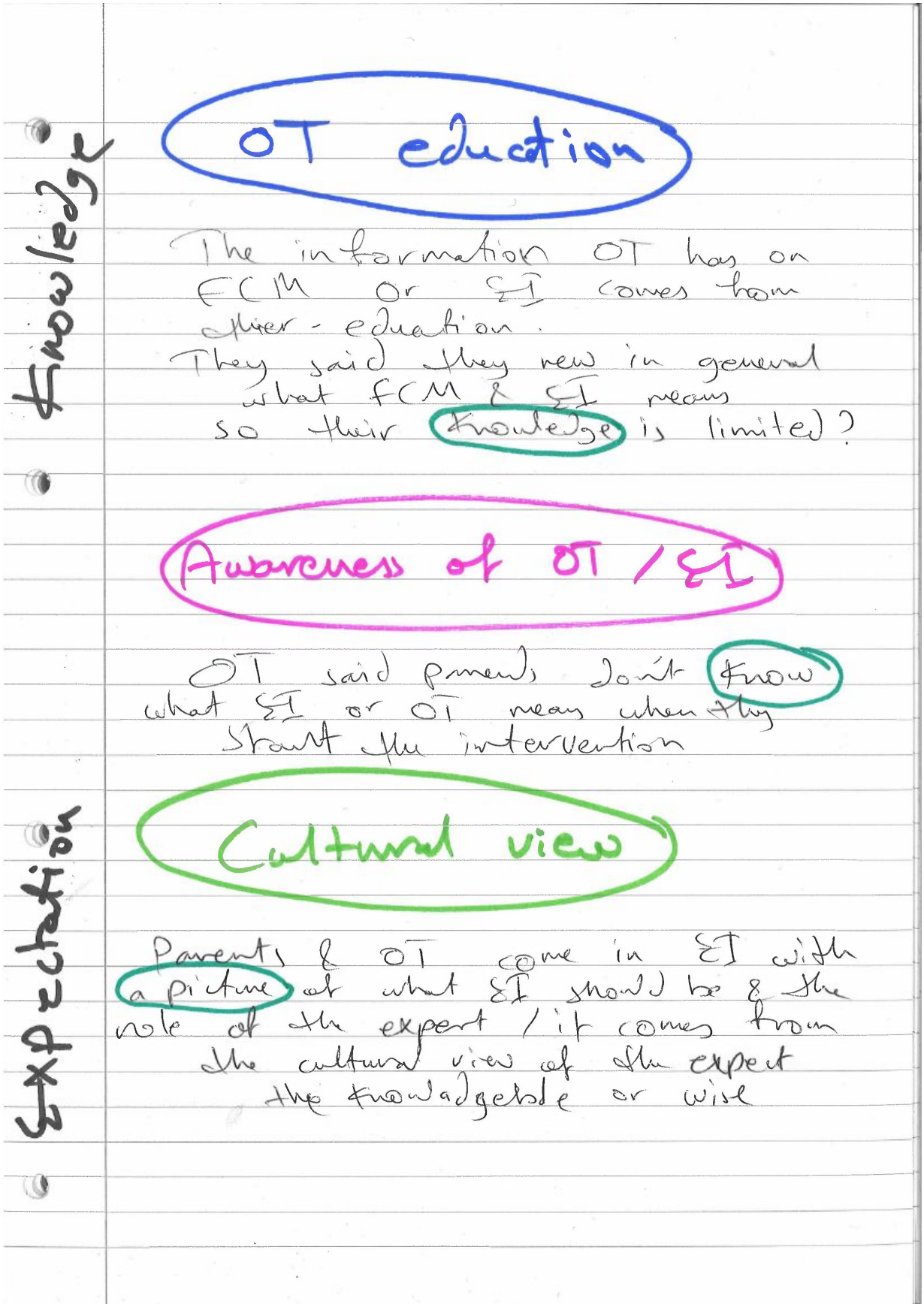
Appendix 15: Second phase OT interview themes



Appendix 16: The power imbalance theme development from findings



Appendix 17: The theoretical framework elements generated from themes



Engagement

OT like a family

This is the view the parents have towards OT
could be related to how supportive the OT are

So → how OT engage in intervention makes parents feel they are "like family"

Expectation

They are the expert

Parents perceive OT as the expert
they expect OT to be the expert

Parent as trainee or Assistant

OT percieve Parent as trainee this is their expectations?

or is it how parents are engaging in EI ?