



Resilience, absorptive capacity, and compassion : the case of the parents of children with disability in a highly fragmented healthcare system

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« Dunia GHANNAM »

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« The case of the parents of children with disability in a highly fragmented healthcare system. »

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Resilience, absorptive capacity, and compassion is not only the title of my dissertation but of my doctoral research journey as well.

Doctoral research journey is so unique. It is an adventurous experience in normal situations, thus how would be for a mother doing research amid a historical national economic crisis, a revolution, a horrendous explosion at the heart of Beirut and worldwide pandemic.

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Dedication

To Ibrahim, Ayman, Yasmina & Yara

Abstract

Payment systems such the French T2A (Tarification À l'Activité) for hospital acute care or fee-per-service systems are incentivizing healthcare professionals to increase the services for which they can bill. This impacts the quality of care; professional ethics are challenged, and reifying phenomena may develop. Competition among healthcare providers increases as well as its fragmentation and the discontinuity of care that it favors. Individuals who suffer the most from this fragmentation are those who need the interference of multiple care providers over extended periods of time such as persons with disabilities.

This research aims at exploring the challenges raised by fragmentation from the patient side and how it becomes possible to overcome the missing links of the chain care, from the case of children born with disabilities in a highly fragmented system such as Lebanon. Twenty-nine semi-structured interviews were conducted with parents of children born with disabilities. It is the first to address such phenomenon through a phenomenological perspective and processual approach based on multiple frameworks. The exceptional empirical material collected enables us to identify the key stages where the system dysfunction and to analyze how it impacts the parents. The roles embraced by the parents informally highlight the improvements to be brought to the system. Our findings also provide a novel analysis of the processes by which parents' resilience enacts and the conditions of success under which compassion organizing solutions are initiated and implemented by some parents triggering collective action by shifting from knowledge brokers to organizational emotion brokers.

This thesis contributes to the body of literature on absorptive capacity and compassion organizing, it also modelizes the process through which an individual outsider to an

organization goes through to design, initiate, and implement an organizational solution to respond to an unmet need. This leads to propose a conceptual model of Compassion Brokering processes. This research also provides a series of practical recommendations to existing and future healthcare providers.

Keywords: Inequity of care, Resilience, Knowledge broker, Absorptive Capacity, Compassion, Compassion organizing, organizational emotion broker, Children with disabilities.

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Condensé de thèse

Les systèmes de paiement prospectifs comme la T2A (Tarification À l'Activité) française pour les soins aigus hospitaliers ou les systèmes de paiement à l'acte pour la médecine de ville française (ex. ophtalmologistes, gynécologues, urologues, etc.) mettent en place un régime incitatif poussant les professionnels de santé à augmenter le nombre de patients traités. En effet, le niveau d'activité clinique constitue la seule variable par laquelle ils peuvent s'ajuster pour maximiser l'enveloppe financière de l'unité clinique (pour les hôpitaux) ou leur propre salaire (pour la médecine de ville). Cela conduit à rechercher une augmentation continue du nombre de « cas » dans un environnement concurrentiel avec de possibles effets négatifs significatifs comme le montraient Angelé-Halgand et Garrot (2014) pour le cas français bien avant la pandémie de COVID-19. Par conséquent, la qualité des soins peut être impactée, la pertinence des soins entamée l'éthique professionnelle remise en question, des phénomènes de réification peuvent se développer impactant à la fois les patients et les professionnels de santé qui peuvent connaître des épisodes d'épuisement, voire changer de métier. La récente crise sanitaire vient amplifier la pression sur les professionnels de santé avec des vagues de démissions accroissant encore la difficulté de rendre attractifs les métiers de la santé pour les diplômés comme pour les étudiants.

Les réformes de santé inspirées par le « Nouveau Management Public » et les systèmes de financement associés comme le paiement prospectif et/ou les techniques managériales comme le Lean management ont continuellement augmenté la pression du contrôle d'efficience à chaque étape de la chaîne de soins favorisant la fragmentation du système comme effet secondaire de cette financiarisation depuis 30 ans en Europe. En mai 2022, le réseau français des biologistes indépendants dénonçait les dangers d'une trop grande financiarisation des soins

sous-tendant la dégradation du service rendu (Chaffin, 2022). En juillet 2022, l'Académie Française de Médecine s'est inquiétée de la financiarisation de la radiologie soulignant son impact sur la qualité du diagnostic, la santé des patients et le coût pour la société (SMPF, 2022). La « financiarisation » désigne « le rôle croissant des motifs financiers, des marchés financiers, des acteurs et des institutions financières dans le fonctionnement des économies nationale et internationales » (Epstein, 2005, pp. 3–16). En France, le principal moteur de la financiarisation des soins de santé a été le système de paiement prospectif introduit par la réforme T2A (Angelé-Halgand & Garrot, 2015) et effectif depuis 2008 (Georgescu & Naro, 2012).

Gageant que la financiarisation ne se réduise pas à un effet de mode mais qu'elle constitue une tendance de fond pour les années à venir, la continuité des soins est susceptible de devenir un défi majeur pour les systèmes de santé dans le monde. L'objectif de cette recherche est d'aborder cette question de la discontinuité des soins. Cela nous a conduit à nous concentrer sur un cas hautement fragmenté, et à choisir le système de santé libanais. Plus précisément nous nous penchons sur le parcours de soins des enfants nés avec un handicap pour la complexité et l'évolutivité des cas qu'ils sous-tendent, qui font de la continuité des soins dans le temps un prérequis de la qualité des soins. Plutôt que d'aborder la question du côté des offreurs de soins, nous avons choisi de le faire du côté du patient, ce qui confère à cette recherche une grande partie de son originalité. La perspective du patient est ici représentée par les parents de l'enfant.

Cette recherche vise à mettre en lumière et à investiguer, d'un point de vue phénoménologique et selon une approche processuelle, les défis organisationnels vécus par les parents d'enfants en situation de handicap dans des systèmes de santé hautement fragmentés.

Notre objectif est de mieux comprendre comment les parents d'enfants handicapés répondent dans un tel contexte à ces défis. Précisément, nous tenterons de répondre aux questions suivantes :

1. Quels sont les défis rencontrés par les parents d'enfants nés avec un handicap dans des systèmes de santé hautement fragmentés ?
2. Comment les parents d'enfants nés avec un handicap réagissent-ils aux défis auxquels ils sont confrontés ?
3. Par quel processus les parents d'enfants nés avec un handicap deviennent-ils résilients ?
4. Comment les parents d'enfants handicapés parviennent-ils à développer des solutions aux défis qu'ils rencontrent ?

Méthodologie et contexte

Le système de santé pluraliste libanais est constitué de deux parties : le public et le privé. Ce dernier est divisé entre une partie à but non lucratif et une autre à but lucratif (Asmar, 2011). Le secteur privé à but non lucratif comprend les centres de soins de santé primaires, les établissements de soins infirmiers et de réadaptation. Les organisations non gouvernementales gèrent cette partie. Le secteur privé à but lucratif comprend les hôpitaux privés, les cliniques privées, les centres de diagnostic ambulatoires comme les laboratoires et les centres de radiologie. Les bailleurs de fonds et les fournisseurs interviennent en tant qu'acteurs privés, publics et public-privé. Le système, dans son ensemble, est hautement fragmenté. Le Ministère de la Santé publique (MOPH) est à la fois l'organisme de réglementation et le principal bailleur de fonds, mais l'acteur influant est le secteur privé qui est également le principal fournisseur de services (OMS, 2012a).

De plus, le système comprend plusieurs agences de financement publiques distinctes du ministère, qui achètent des services auprès de prestataires publics et privés. Au-delà, l'origine des financements se retrouve dans des budgets gouvernementaux, des dons ou des prêts de partenaires de développement internationaux, tels que la Banque mondiale, l'Union européenne, des organisations internationales de la santé, ou encore les ambassades (Ayoub & Mahdi, 2018).

Le système s'appuie fortement sur des professionnels libéraux et des prestataires privés qui se font concurrence. Le mécanisme de paiement à l'acte récompense les prestataires pour le volume des services et non pour la qualité du service (Korda & Eldridge, 2011). Le système manque d'un système d'information unifié et d'une coordination entre les unités de soins.

Le système de santé libanais est un parfait représentant d'un système hautement fragmenté et priorisant le profit, avec de multiples organes directeurs aux pouvoirs limités.

Cette fragmentation affecte particulièrement les personnes handicapées qui ont besoin de multiples services de soins sur de longues périodes.

Pour analyser ces défis et étudier les expériences vécues des parents d'enfants nés avec un handicap, nous avons adopté une approche interprétative phénoménologique. Nous avons mené une recherche qualitative qui commence de manière inductive, puis se développe en adoptant une approche abductive. Vingt-neuf entretiens semi-structurés ont été menés auprès de parents d'enfants nés avec un handicap. Notre recherche suit une approche phénoménologique interprétativiste qui permet d'enquêter sur les expériences vécues des personnes et d'explorer comment elles donnent du sens à ces expériences (Smith & Osborn, 2003, 2015). La phénoménologie permet au chercheur de se concentrer sur les expériences communes et non

individuelles vécues par les participants face à un phénomène tel que la prise en charge du handicap dans un système de santé hautement fragmenté (Creswell, 2007).

Notre approche combine les engagements interprétatifs et phénoménologiques. Le paradigme interprétatif permet de contextualiser et de « donner du sens » aux expériences des participants, tandis que l'approche phénoménologique donne la parole aux participants (Larkin et al., 2006).

Résultats

Les résultats de cette thèse seront présentés en lien avec la question de recherche à laquelle ils répondent

1- Quels sont les défis rencontrés par les parents d'enfants nés avec un handicap dans des systèmes de santé hautement fragmentés ?

Nous avons répondu à notre première question de recherche en analysant et en caractérisant les défis auxquels sont confrontés les parents d'enfants nés avec un handicap dans un système hautement fragmenté. Nous avons constaté que dans un tel contexte, le fardeau financier et le manque de soutien se révèlent particulièrement pesants pour les parents. Nous avons également présenté des expressions concrètes d'inéquité résultant de ce système de santé hautement fragmenté. De plus, nous proposons quelques éléments clés permettant d'identifier les racines du manque de compassion qui se développe dans un tel contexte.

2. Comment les parents d'enfants nés avec un handicap réagissent-ils aux défis auxquels ils sont confrontés ?

Concernant notre deuxième question de recherche, notre recherche révèle également que les parents d'enfants nés avec un handicap ont assumé de manière informelle des rôles

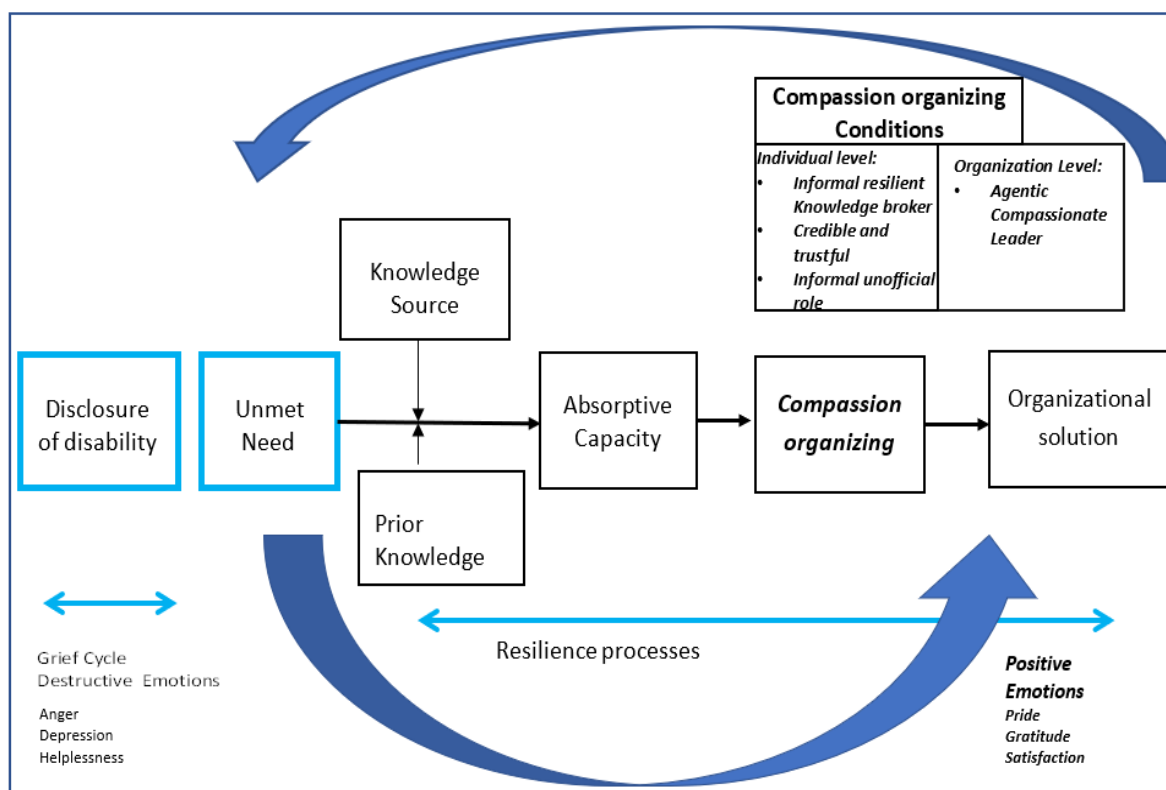
professionnels, tels que le patient expert et le gestionnaire de cas, afin de surmonter ces défis, en comblant les lacunes du système.

3. Par quel processus les parents d'enfants nés avec un handicap deviennent-ils résilients ?

Concernant notre troisième question de recherche, notre recherche montre que les parents d'enfants handicapés sont passés par un processus de deuil après l'annonce du handicap de leur enfant. Ensuite, ils sont devenus résilients en donnant un sens à l'adversité, mobilisé des ressources et développé des processus de communication et de résolution de problèmes.

4. Comment les parents d'enfants nés avec un handicap parviennent-ils à développer des solutions aux défis qu'ils rencontrent ?

Abordant également notre quatrième question de recherche par une approche processuelle, notre recherche révèle que les parents d'enfants nés avec un handicap sont devenus des courtiers organisationnels informels en émotions en absorbant des connaissances et en déclenchant la compassion dans une organisation d'accueil qu'ils ont choisie.



New element from Cohen and Levinthal (1990)	
New element from Dutton et al. (2006)	All elements in bold and italic

L'annonce du handicap de leur nourrisson constitue un traumatisme majeur pour les parents. Ils subissent également l'inéquité et le manque de compassion d'un système de soins hautement fragmenté. Ils entrent alors dans le cycle du deuil. Plus tard, ils commencent à initier des processus de résilience et à assimiler des connaissances. Ils ont l'idée d'une solution répondant à leurs besoins et décident d'en faire une solution organisationnelle. À ce stade, ils passent de l'état d'une personne résiliente au statut d'un courtier de connaissances informel.

Pour mener à bien leur projet, ils ont besoin de ressources disponibles dans les organisations. Ils en viennent ainsi à devoir déclencher l'organisation de la compassion au sein d'une

organisation ciblée et à en convaincre les acteurs clé de contribuer à la réalisation de leur projet. À ce stade, ils deviennent des courtiers (ou des « passeurs ») en compassion.

En réussissant à convaincre le dirigeant de l'organisation ciblée, ils permettent à leur idée de devenir réalité. Étant donné que la compassion déclenche des émotions positives qui fédèrent les personnes concernées ou témoins d'un acte de compassion autour du projet, nous considérons que les parents se transforment en courtiers en émotions organisationnelles.

Le cycle de métamorphose a fait passer le parent d'un individu traumatisé à un courtier en émotions organisationnelles.

Contributions

Les résultats de la recherche présentés dans cette thèse apportent de multiples contributions pratiques, empiriques et théoriques.

Contributions pratiques :

- Former les professionnels de santé actuels et futurs sur la façon d'informer la mère ayant donné naissance à un enfant handicapé. Cela peut se faire en intégrant un cours de psychologie appliquée dans le cursus de formation des médecins la faculté de médecine, comme c'est le cas dans certaines facultés comme à Nantes.
- Faire une place aux parents experts du patient dans l'équipe soignante, ce qui implique également de former les personnels médicaux et paramédicaux et les étudiants à accueillir ce nouvel acteur, à lui faire une place dans le cadre d'un travail d'équipe reconnaissant les apports de chacun, et à apprendre à travailler avec lui/elle.

- Mettre en place un questionnaire de parcours de soins qui pourrait être l'un des parents du patient expert. Cela contribuerait à réduire la vulnérabilité financière du parent de l'enfant handicapé et valoriserait l'expertise développée en la reconnaissant formellement dans le système de santé.

Contributions empiriques :

- Cette thèse est une enquête sur les expériences de parents d'enfants nées avec un handicap dans des contextes complexes et hautement fragmentés comme le système de soins du Liban.
- Les résultats de cette recherche peuvent être pertinents pour d'autres systèmes de santé hautement fragmentés et appellent des travaux futurs pour explorer leur validité externe.
- Nos résultats peuvent être proposés comme l'ébauche d'un checking list pour évaluer les systèmes de soins, à consolider dans le cadre de recherches complémentaires.

Contributions théoriques :

- Notre recherche est également la première à adopter plusieurs cadres pour comprendre ce phénomène à travers une approche processuelle.
- En ce qui concerne la littérature sur la capacité d'absorption, la recherche est la première à examiner le processus par lequel un individu, étranger à une organisation, devient un courtier de connaissances. Bien que nous ayons pu trouver dans la littérature des travaux portant sur la manière dont l'employé contribue au courtage de connaissances dans les organisations (Lane et al., 2006 ; Schweisfurth & Raasch, 2018), notre revue de la littérature n'a pas identifié de recherche sur les courtiers de connaissances extérieurs aux organisations. De plus, notre recherche montre que dans un contexte spécifique, les

« régimes d'appropriabilité » du modèle de capacité d'absorption de Cohen et Levinthal (1990), ne sont pas pertinents. Cependant, nous avons identifié à partir de nos données empiriques un élément d'activation, inexistant dans le modèle mentionné précédemment, qui est le déclencheur du courtage de connaissances. Ceci est apparu comme un élément essentiel de notre modèle.

- En ce qui concerne la littérature sur l'organisation de la compassion, nos résultats suggèrent que l'initiation d'un processus d'organisation de la compassion au sein d'une organisation peut être possible sous deux conditions : 1-la personne souffrante (qu'elle soit externe ou interne à l'organisation) doit être un courtier de connaissances résilient pour jouer des rôles informels et non officiels au sein de l'organisation et 2-l'organisation doit avoir un leader compassionnel, capable de partager la douleur du parent.
- Notre contribution finale est le modèle de courtage organisationnel des émotions qui intègre la capacité des personnes souffrantes à identifier leurs besoins non satisfaits, à absorber les connaissances pertinentes, à localiser les ressources et à déclencher un processus d'organisation de la compassion pour soulager leur propre souffrance et celle des autres. Ce modèle met en évidence qu'il existe un processus par lequel un tiers en vient à proposer une solution organisationnelle pour répondre à un besoin non satisfait. Ce processus intègre la capacité d'absorption, la résilience et l'organisation de la compassion, ainsi que la transformation des émotions destructrices en émotions positives qui vont fédérer les énergies autour d'un projet réparateur.

General Introduction

Prospective payment systems like the French T2A (Tarification À l'Activité) for hospital acute care or fee-per-service systems like the French medical consultants (e.g., ophtalmologists, gynecologists, urologists, etc...) are enacting an incentive regime urging healthcare professionals to increase the number of patients discharged. Indeed, the clinical activity level constitutes the only variable by which they can adjust to save or raise the clinical unit financial envelope (for hospitals) or their own wages (for consultants). This leads to a search for continuous increase of the number of « cases » in a competitive environment with possible significative negative effects as shown by Angelé-Halgand et Garrot (2014) for the French case well before the COVID-19 pandemic. Consequently, quality of care may be impacted, care relevance raised, professional ethics challenged, reifying phenomena may develop impacting both patients and health professionals who can experience burn-out episodes or change jobs. The global healthcare crisis has just amplified the pressure on health professionals with waves of resignations making it even more difficult to attract both candidates on healthcare jobs and students on healthcare curricula.

Similar negative consequences can be identified in the case of introducing managerial techniques as lean management designed for increasing the efficiency of hospital units like operating theatres (Mahmoud & Angelé-Halgand, 2019) In both cases, raising financial revenues becomes the priority and is integrated as such by healthcare professionals and especially medical doctors considered as the main decision makers as well as revenue raisers and expense drivers.

One of the critical effects highlighted is an increased competition between providers and a fragmentation of the system that again may impact quality of care through a series of phenomena like discontinuity of care or delays to access to the relevant care in time. Fragmented healthcare systems where providers are “focused and acting on the parts without adequately appreciating their relation to the evolving whole, is perceived as the root of unsustainable cost increases, poor quality, and inequity” (Stange, 2009).

The uncertain future of the MAIA (Méthode d’Action pour l’Intégration des services d’aide et de soins dans le champ de l’Autonomie), one of the very few French attempts to overcome fragmentation and the associated lack of coordination of healthcare professionals into a chain of care and that aimed to integrate them into some forms of consolidated network shows how difficult it is to change the system (Karim et al., 2020). Under such an incentive regime physicians may not be willing to accept roles they are not reimbursed for (Mossialos et al., 2005).

New Public Management inspired healthcare reforms and associated funding systems like prospective payment and/or managerialist techniques like lean management have continuously increased the pressure to perform at each given stage of the chain care favoring the system fragmentation as a side effect of this financialization drive since 30 years now in Europe. In May, 2022, the French independent biologist network denounced the dangers of too much financializing healthcare underlying the deterioration of the provided service (Chaffin, 2022). On July 2022, the French Academy of Medicine worried about the financialization of radiology stressing its impact on the quality of the diagnosis, the health of the patients and the cost for society (SMPF, 2022). Financialization relates to the increasing role of financial motives,

actors and institutions in the way by which economies are run on both national and worldwide scales. In France, the main driver of financialization of healthcare has been the prospective payment system introduced by the T2A reform (Angelé-Halgand & Garrot, 2015) and has been effective since 2008 (Georgescu & Naro, 2012).

Assuming that financialization is not a fleeting trend but rather a fundamental trend for the years to come, discontinuity of care is likely to become a crucial challenge for healthcare systems worldwide. Reid, Haggerty and McKendry define continuity of care as being ” *how one patient experiences care over time as coherent and linked; this is the result of good information flow, good interpersonal skills and good coordination of care* ” (Reid et al., 2002). The objective of this research is to address this issue of discontinuity of care. This led us to focus on a highly fragmented case, with the Lebanese healthcare system. Indeed, the Lebanese healthcare system is characterized by informational and relational discontinuity. The system does not foresee a referral system.

Box 1 : Definitions of Informational and Relational continuity

Informational continuity is the availability and use of (patient) information on prior events and circumstances- diagnostic tests, referral recommendation.

Relational continuity acknowledges that sustained contact between a patient and a provider is an undergirding that connects care over time. Seeing the same provider over time encourages informational continuity and is also thought to engender a unique set of benefits such as trust, mutual understanding, and a sustained sense of responsibility toward the patient ”

(R. Reid et al., 2002).

Source (R. Reid et al., 2002)

We chose the care path of children born with disabilities for it is an extremely challenging type of case and because the continuity of care is most crucial in the delivery of care in time, with changing needs over time, and hence determines the quality of care. Rather than addressing the issue from the providing system side we chose to do it from the patient side, which largely gives this research its originality. The perspective of the patient is hence represented by the parents of the child. What challenges does a highly fragmented system as the Lebanese one raises for the parents of a child born with disabilities and how may they react to overcome the missing links of the system? What about the vulnerability of the parents in the relationship with medical doctors who have the relevant knowledge relating the case of their child from the disclosure of the disability of their baby to the following steps leading to accept the unacceptable information of non-reversibility of the disability? The vulnerability may also be financial and lead to increased inequities. Health equity is an ethical and human right (Braveman et al., 2017). By which resilient processes can the parents manage to find solutions to fill the gap of the dysfunctioning system? These are the key questions addressed in this research.

Research questions

This research aims to highlight and investigate, from a phenomenological perspective and using a processual approach, the organizational challenges experienced by parents of children with disabilities in highly fragmented healthcare systems.

Our objective is to better understand how parents of children with disabilities respond in such a context to these challenges. The thesis's central research question is: *"How the parents*

experience and address the challenges raised by having to care for children born with disabilities in a highly fragmented system when rejecting institutionalization?”

In our thesis we will try to respond to the following questions:

1. What are the challenges experienced by parents of children with disabilities in highly fragmented healthcare systems?
2. How do the parents of children with disabilities respond to the challenges they experience?
3. What is the process followed by parents of children with disabilities to become resilient?
4. How do the parents of children with disabilities manage to find solutions to the challenges they have experienced?

Scientific Interests of the topic

The disability topic, and more specifically health care linked to disability, is of major interest to us as a researcher since it is closely linked to lived experiences. Our interest was triggered, independently of our will, in 1997 with the birth of our first child. Since then, we have been confronted daily with the challenges faced by families with a disabled child while navigating through the Lebanese healthcare system to identify and provide the required care.

During these times, we noted that as parents, we had to go through several stages, acquire new knowledge and endorse new roles. Consequently, we realized that at every step of the healthcare process we had to informally fill the gaps of the system embracing new roles, but we also went beyond these roles once we were recognized as such by our direct and indirect

entourage. This was the time of “giving back”, “sharing the experience” and “contributing to improving” the system we were living in.

We had reached a point where we needed to understand more in-depth how parents of children with disabilities had lived similar experiences as it had become clear that it might be the starting point of an organizing journey. This was the starting point of this thesis. This personal experience also enabled us to get access to exceptional material by favoring trust from the interviewee’s side, which gives this research a true novelty nature.

The thesis is organized in two parts: *the first part* deals with the fragmentation of a healthcare system and its impact on parents of children born with disabilities. It includes three chapters.

In the *first chapter*, we present the context of our thesis, the Lebanese healthcare system operating in a fragile context, through a global discussion on the fragmentation of the Lebanese healthcare system and then, more specifically, by using the case of persons with disabilities as representative of such a fragmented system. We aim to familiarize the reader with the functioning of this system and to identify the factors that contribute to the fragmentation of the system. The final section of this chapter presents our epistemological and methodological positioning and is a necessary phase to be able to approach the empirical stage of our study.

In the *second chapter*, we present the failures of a highly fragmented healthcare system.

Finally, in the *third chapter*, we analyze the failures of fragmented healthcare systems.

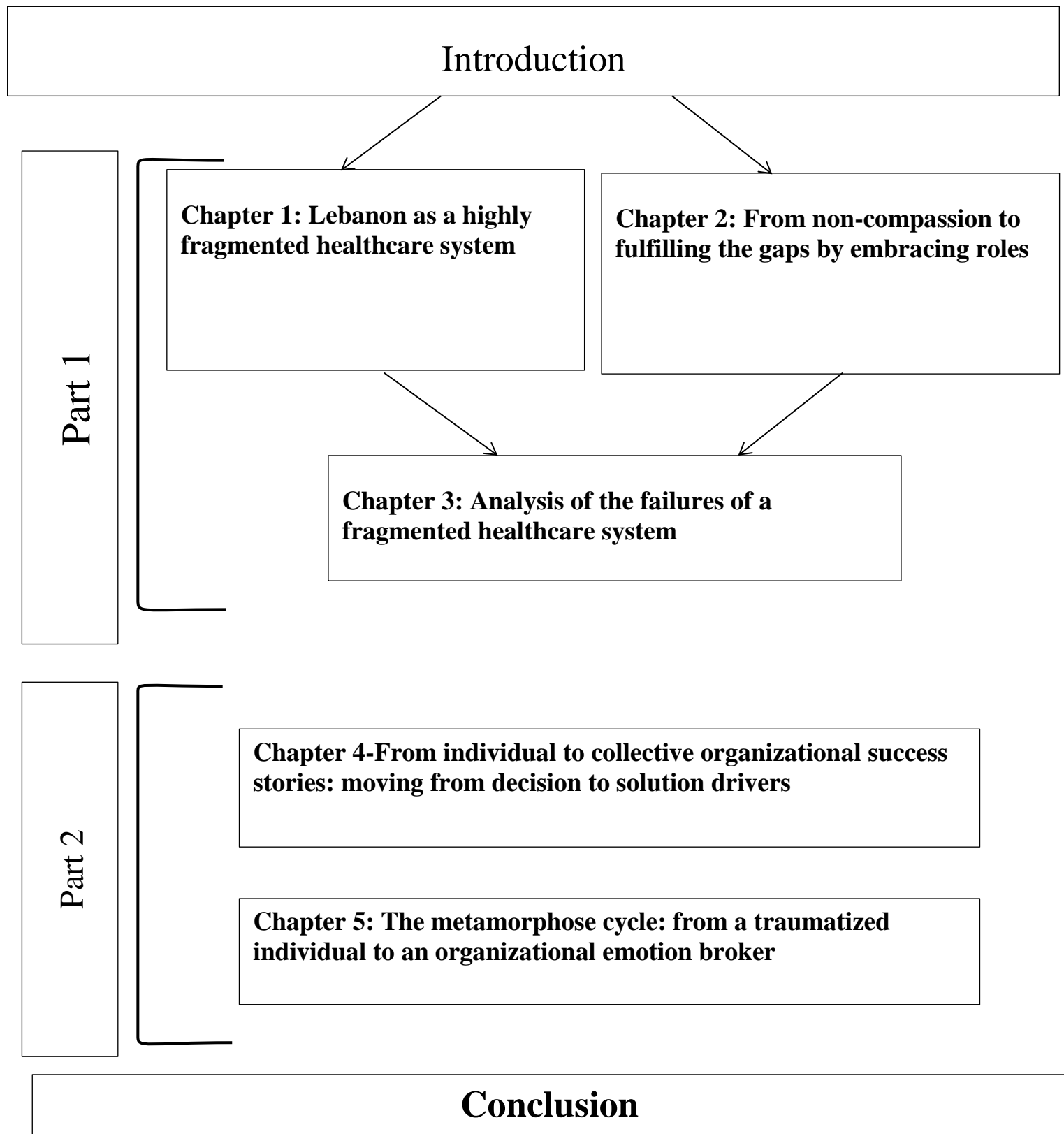
The second part of the thesis presents the emerging solution developed by the parents of children with disabilities to overcome the challenges faced. It includes two chapters. We start this part with the *fourth chapter* which describes the individual solutions adopted by the parents

to overcome these challenges the objective is to understand how those parents could provide the healthcare in this highly fragmented healthcare system. We also tackle the collective organizational success stories which allowed the parents to move from being decision makers to becoming solution drivers. In the *fifth chapter*, we conclude by describing the metamorphose cycle of the parents from traumatized individuals to organizational emotion brokers.

We conclude our work by presenting our contributions, the limits as well as potential new avenues of research.

Figure1 below summarizes the plan of our thesis.

Figure 1-Schematization of the thesis plan



Part I-Healthcare fragmentation and persons with disabilities: from inequity to lack of compassion

This part aims to answer the first research question: “what are the challenges experienced by parents of children with disabilities in highly fragmented healthcare systems?” As well as the second research question: “how do the parents of children with disabilities respond to the challenges they experience?”

The objective of this part is to introduce the problem of this study, its importance, to present the context and to objectivize and analyze the failures of the system.

Part I consists of three chapters. Chapter one is an introductory chapter. It provides the necessary information to explain the context of the study. It is divided in several sections healthcare system fragmentation, Lebanese healthcare context, the research questions, and the methodology. Chapter two objectivizes the challenges of the fragmented healthcare system and analyzes the findings. Chapter three analyzes the failures of the highly fragmented system in the light of inequity of care and compassion organizing literature.

Chapter 1- Lebanon as a highly fragmented healthcare system

This thesis first aims to give a concrete account of the challenges raised by highly fragmented healthcare systems in a fragile setting. Fragmented healthcare occurs when the care is spread among multiple providers who are poorly coordinated (Agha et al., 2017; Stange, 2009). Most healthcare systems developed in a manner that fragmented the care through multiple organizations and governance structures, payment mechanisms, structure barriers such as primary/ secondary and medical / socio-medical healthcare (Nolte et al., 2012).

Fragmentation of healthcare is associated with bad quality of care, preventable errors and high financial costs (Agha et al., 2017; Elhauge, 2010). People with disabilities who usually have complex healthcare needs are among the most affected by the fragmentation of healthcare systems.

Stange (2009) identifies unintended consequences of the healthcare fragmentation like inefficiency, ineffectiveness, inequality, commoditization and depersonalization. The effects of these consequences are amplified in fragile contexts where countries experience severe shocks such as wars, conflicts, and political instabilities (Stephan Yeretdzian, 2022) and governments find themselves unable to provide basic services including healthcare (Ramadan et al., 2021). This fragility turns the public healthcare service unreliable, and help the emergence of unregulated privatized healthcare networks (Hill et al., 2014).

Based on these concepts, this chapter starts with a briefing on healthcare system fragmentation and disability, then it presents the research context. It is divided into three sections. Section 1.1 briefs on the fragmentation of healthcare systems and disability. Section 1.2. presents the

fragile context of the highly fragmented Lebanese healthcare system and the context of persons with disabilities in Lebanon. Section 1.3.the epistemological and methodological foundation of the research foundation.

1.1. Healthcare systems: Fragmentation and Disabilities

Healthcare system fragmentation occurs when “ multiple decision makers make a set of health care decisions that would be made better through unified decision making ”(Elhauge, 2010). Though there is no unique definition for healthcare system fragmentation, scholars have agreed that weak or ineffective coordination among decision makers (governor, financiers, providers) is associated with healthcare system fragmentation.

Enthoven (2009) defined healthcare fragmentation as a “systemic misalignment of incentives, or lack of coordination, that spawns inefficient allocation of resources or harm to patients”. According to Stange (2009) and Cebul et al.(2008) , in fragmented healthcare systems no single entity coordinates effectively the delivery of care that might involves multiple providers and organizations (Frandsen et al., 2015).

Siqueira et al (2021) define healthcare system fragmentation as “the division without explicit means of coordination of functions (e.g. financing, provision) or agents (e.g., payers, providers,) in a healthcare system” . They added that fragmentation is characterized by the “existence of many non-integrated entities that operate without synergy and often in competitions and encompass a lack of coordination among organizations, functions, and governance systems” (Siqueira et al., 2021).

In such systems, providers caring for the same patient do not regularly communicate with each other’s (Kern et al., 2019). Each provider focuses on one part of the patient without having a holistic view of the individual as a whole (Stange, 2009). The poor quality of healthcare might be explained by the presence of gaps in care , no single provider can ensure that the entire

patient's needs are taken into account and no major health issues are missed. While the high financial costs could result from the unnecessary duplication of services. given the poor exchange of clinical data among the providers. This poor coordination among providers may lead to missing important healthcare issues, poor patient outcomes, and unnecessary or even harmful services (Agha et al., 2017; Elhauge, 2010; Stange, 2009).

Healthcare system fragmentation could occur at multiple levels. There could be governance fragmentation, financing fragmentation, providers fragmentation and service provision fragmentation (Stephan Yeretizian, 2022).

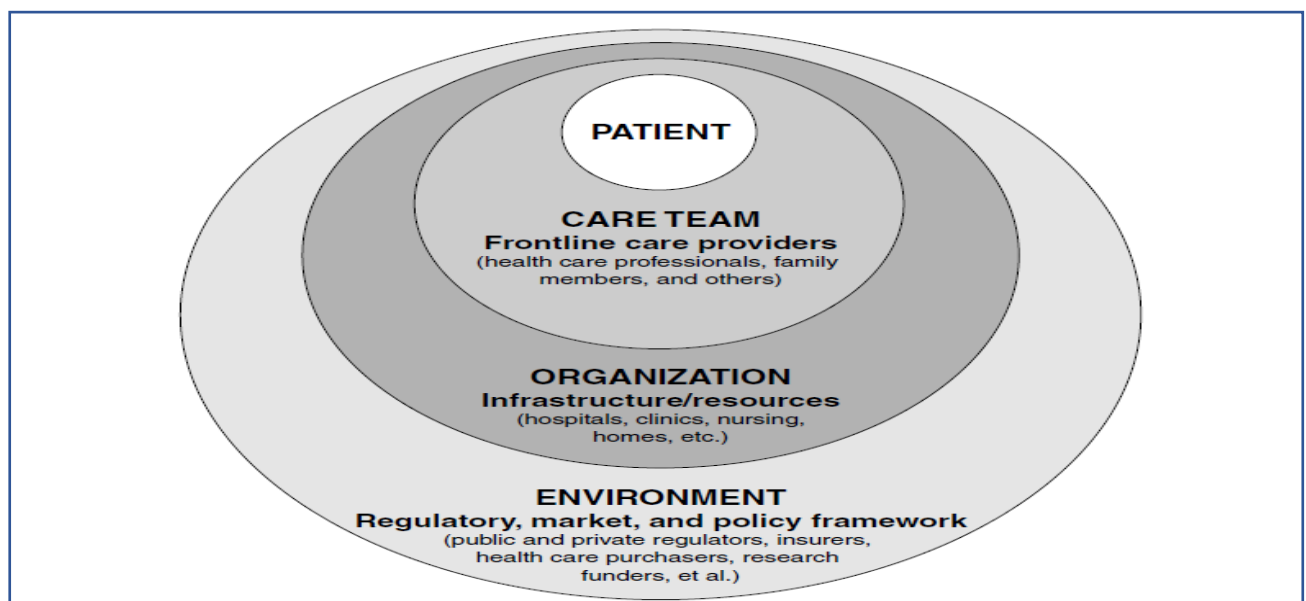
Conversely, high-quality care is associated with the continuity of care (Beadles et al., 2014) especially for patients with disabilities who usually need multiple or complex health services including rehabilitation, which necessitate input from various healthcare providers. Disability is an umbrella term for impairment, activity limitations and participation restriction (WHO 2001). Impairments are “*problems in body function or alterations in body structure – for example, paralysis or blindness*” (WHO 2011). Disability may result in a wide range of health conditions, for example Down syndrome, development delays, or skeletal deformities, which leads to a diversified range of impairments, including mobility, mental, sensory and communication. The needs of persons with disabilities may extend across services in different sectors such as education and social (WHO 2011). Hence, they suffer the most from the fragmentation of healthcare system.

While a good health system is a system that “*...delivers quality services to all people, when and where they need them. The exact configuration of services varies from country to country, but in all cases it requires a robust financing mechanism; a well-trained and adequately paid*

workforce; reliable information on which to base decisions and policies; well-maintained facilities and logistics to deliver quality medicines and technologies” (World Health Organization, 2017).

This system is composed of many levels, Reid et al.(2013) proposed a conceptual framework of the healthcare levels. The framework has four “nested” levels: the individual, the care team, the organization, and the environment.

Figure 2: Conceptual drawing of four levels of healthcare system



Source: (Reid et al., 2005)

The patient is at the center, nested in the care team level which includes the care providers, the patient and family members; the organization level which provides the infrastructure such as hospital, clinic, nursing home; the last level is the political and economic environment (governance, regulation, financial, payment and other) which set the conditions under which the previous three levels operate (Reid et al., 2005).

Despite that the health of a population and its livelihood is affected by the performance of the health systems (Enthoven, 2009), healthcare systems worldwide suffer from fragmentation of care.

This fragmentation affects negatively the cost, quality and outcome and sometimes might lead to the loss of lives (Enthoven, 2009). A fragmented healthcare has been associated with poor quality, overutilization of resources (Cheng et al., 2011) and preventable medical errors (Elhauge, 2010).

Having introduced healthcare fragmentation and disability; section 1.2. provides an overview of the Lebanese healthcare system as a highly fragmented healthcare system.

1.2. The research context: Lebanon as a highly fragmented healthcare system in a fragile setting

Lebanon experienced a myriad of political, social, and economic hardships due to extended periods of conflicts. This fragile context led to limited governance capacity and inadequate public services (Khalife et al., 2017). The long period of fragility weakened the public sector and contributed to the development of private institutions and nongovernmental organizations (NGO) (Stephan Yeretizian, 2022).

Currently, the Lebanese healthcare system is a highly fragmented system with a mix of public and private providers and payers (Ammar et al., 2007; Khalife et al., 2017). The Ministry of Public Health (MOPH) has a weak regulatory presence that encouraged an unregulated growth of the private sector and led to oversupply of healthcare services.

What follows presents in section 1.2.1. the socio-political context of the Lebanese care system since the war of 1975 till the current economic crisis while section 1.2.2. provides an overview of the Lebanese healthcare system.

1.2.1 Lebanese healthcare system as a very turbulent socio-political context

Lebanon has suffered from a civil war that lasted around eighteen years (1975-1992) then two wars in 1996 and 2006 and a prolonged period of political conflict and instability. The prolonged periods of conflicts led to a “shrinking economy, limited governance capacity and inadequate public services across sectors” (Khalife et al., 2017). The weakening of the public sector was accompanied by growth and development in the private institutions and the nongovernmental organizations (NGO) representing the majority of hospitals in Lebanon

(Khalife et al., 2017). The freedom to establish a business in a deregulated environment with limited government control has attracted Lebanese entrepreneurs to investment in healthcare service as financing agent or as a provider (Ammar et al., 2007). The unregulated growth caused an oversupply of healthcare services and created a supply- induced demand (Ammar, 2003). Lobbies have emerged out of the rising number of private for- profit hospitals and medical professionals, they competed for their access to clientele, to “out-of-pockets payments and public money” (Lerberghe et al., 2018). The reimbursement system has incentivized providers to commodify healthcare services; the more hospitalizations, surgical interventions, consultations, diagnostic tests , the “higher the income to keep their enterprises thriving” (Lerberghe et al., 2018). “Ambulatory care had become the prime example of fragmented consumption of health commodities, with overbilling of patients, supply induced demand and low standards of care”(Lerberghe et al., 2018). The provision of healthcare service targets profit maximization rather than quality of care (Ammar et al., 2007). Consequently, poor regions and vulnerable individuals are not attractive to private, profit-oriented enterprises; this negatively affects the equity of care.

This competitive and unregulated environment intensifies the adverse consequences of fragmentation, the for-profit corporations usually maintain their proper ethics, policies, procedures, data systems. Competition in an over supplied unregulated environment is even more aggressive which is the case in Lebanon because the previous hospital accreditation system that reigned from 1983 till 2001 was linked to the complexity and quantity of medical services offered and this incentivized providers to invest in sophisticated equipment and complex services without rational planning (Ammar et al., 2013). As a result, overutilization

and increased hospitalization costs were experienced due to lack of regulations especially at the supply side and in the presence of a supplier-induced demand.

This excess in supply in an unregulated environment might pose problems related to the efficiency of treatment prescribed and the procedures applied. The issuance of laws to regulate and govern the private sector has “proved to be fragile in view of free market, and their implementation has been remained weak” (WHO, 2012a).

After this period of chaos, the MOPH started to gain power over hospitals, mainly because the public sector is the major financier of the hospitalization care almost 64% of the income of private hospital comes from public financing (WHO, 2012). MOPH imposed an accreditation system on hospitals that provide services to the public sector and this accreditation evolved over the years, it improved MOPH negotiating position to improve the quality of care and to decrease the expenditure on hospitalization. MOPH gains influence over hospital where it purchases uninsured patient care, but it had no financial leverage to influence ambulatory care where individuals healthcare providers work without negotiated fee-setting or regulatory framework(Lerberghe et al., 2018). Having little leverage over private-for-profit ambulatory care, MOPH focused on collaborating with NGOs and municipalities to create the “National Primary Health Care” network which provides primary health care (PHC) services care to all Lebanese citizens. These healthcare centers contract with MOPH that supports them with in-kind donations: guidelines, training, educational materials, vaccines, medical supplies while they provide generalist and specialized outpatient services to inhabitants. The contract does not discriminate between insured and uninsured patients, they all pay the same fees, thus offering affordable care with good quality. MOPH’s support has improved access and quality of care,

but the national PHC network has not moved from fragmented specialist outpatient care to people centered primary care. In addition, the contracted network is not alone at the level of the country, there are the individual private clinics, the hospital's out-patient department and the NGO's centers that are not yet part of the national network and these represent the majority of outpatient contacts (Lerberghe et al., 2018), there is no accurate information on the expenditures on primary healthcare services (WHO, 2017) nor on the total volume of outpatient contact per year (Lerberghe et al., 2018).

During the process of restructuring after several wars 1975-1996-2006, the healthcare sector is faced by the refugees' crisis. The population has increased by around 30% since 2011 which imposes pressure on the country care sector (Baroud & Mouheildine, 2018). Recently, the country is classified as "fragile and conflict-affected country" (Hill et al., 2014). The collapse of the economy and the devaluation of the local currency and the banks' constraints on deposits increases poverty and unemployment rates. Currently, the role MOPH as a regulator of the healthcare system is threatened because this fragile context would intensify the weakness of the public sector.

1.2.2. Lebanese healthcare system: a fragmented pluralistic system

The Lebanese healthcare system is a fragmented mix of public – private healthcare providers and financers. The prolonged period of wars and instability weakened the public sector and allowed the private sector to become the dominant service provider.

The system is fragmented at the levels of governance, financing, professionals, provisions, and patient pathway.

The governance of the healthcare system is divided between two ministries: the MOPH and the Ministry of Social Affairs (MOSA). The MOPH governs the medical services. It oversees the primary healthcare centers and public hospitals. It is responsible for the accreditation of hospitals and the licensing of medical healthcare providers, collecting medical information, and following up the patient's complaints. While the MOSA is the entity governing the socio-medical services. It has limited influence over the socio-medical professionals who are obliged to get a license. The Lebanese healthcare system is highly fragmented at the level of financing since the fragmentation touches various financing dimensions (Siqueira et al., 2021). There are many financers, the MOPH, multiple social financing agents, private insurance companies, and households. Each financer has its own benefits packages, groups of beneficiaries, combinations of premium, and a specific imposed co-payment percentage. Lebanon has an expensive healthcare system with a high out of pocket health expenditure which exposes householders to financial risks (Ibrahim & Daneshvar, 2018) The healthcare professionals are liberal professionals who usually own their private clinics who are paid on fee-per-service basis. They are not demanded to coordinate the patient care. The healthcare provision in Lebanon relies mainly on the private sector. The patient path lacks a gatekeeper. The patients are free to choose the providers. The benefits vary according to the financer and co-payments are usually imposed on the patient.

Table 1: Characteristics Lebanese healthcare system

Feature	Characteristics
Access	<ul style="list-style-type: none">• Absence of gatekeeper• Free circulation inside the system
Patient Choice	<ul style="list-style-type: none">• Free choice of physicians• Free choice of healthcare establishments (primary care, hospital, ambulatory...)
Benefits	<ul style="list-style-type: none">• Long term illness fully covered• Socio-medical services not fully covered and excluded by some financers• Dental and Glasses excluded
Financing	<ul style="list-style-type: none">• Co-payment• Private insurance to cover co-payment• Multiplicity of programs.• Widespread informal payment
Remuneration of providers	<ul style="list-style-type: none">• Fee per service
State Role	<ul style="list-style-type: none">• Limited power of the MOPH and MOSA

Prepared by the author inspired from (Kutzin, 2011)

What follows presents the fragmentation of the Lebanese healthcare system at different levels.

1.2.2.2. Healthcare system organization and governance: a fragmented governance

The governance of the healthcare systems involves setting the policy of the system, regulating different functions, levels and actors, coordinating actors , allocating resources and ensuring accountability toward stakeholders (Olmen et al., 2012)

The Lebanese healthcare system is divided between medical care and socio-medical care. These healthcare services are under the governance of two ministries. The Ministry of Public Health (MOPH) oversees the medical healthcare system while the Ministry of Social Affairs governs the socio-medical healthcare system.

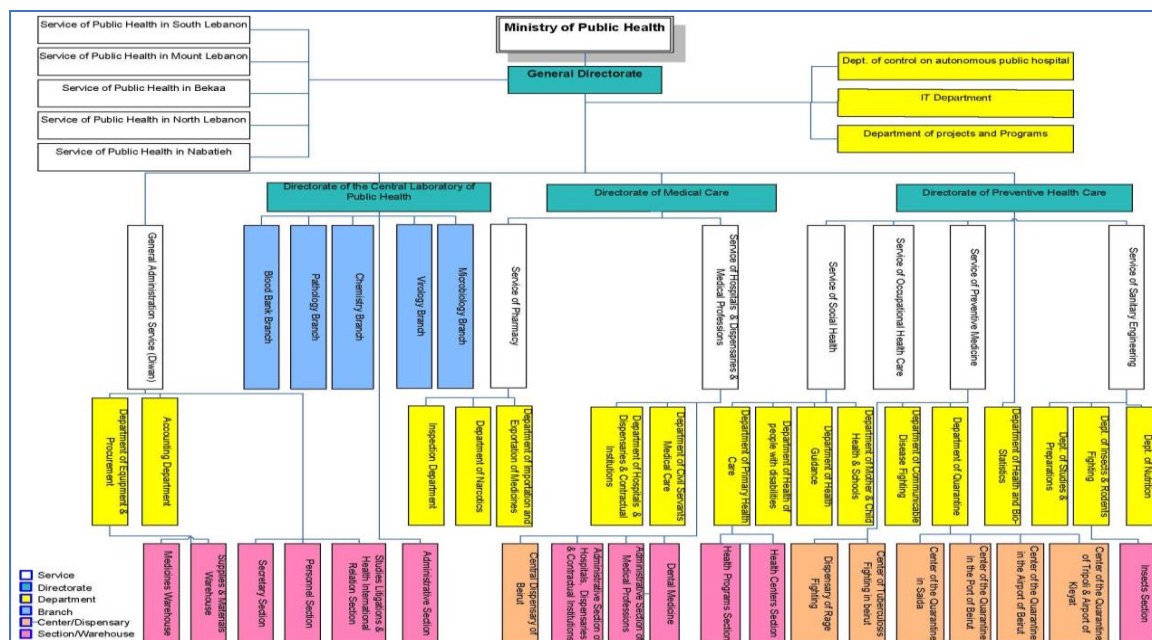
The role of the Ministry of Public Health

The MOPH oversees the functioning of the healthcare system through governing the primary healthcare centers and the public hospitals, signing contract to cover hospitalization fees of the uninsured Lebanese citizens, issuing accreditation for hospitals, licensing medical healthcare professionals, collecting information on health situation and following up patients complains.

The MOPH governs the primary healthcare centers network and has four services: social health, occupational healthcare, preventive medicine, and sanitary engineering(Ministry of Public Health, 2019) .

The MOPH pilots a national network of primary healthcare centers scattered in the country, these centers are owned by NGOs, municipalities and MOSA.

Figure 3: Organization chart of the ministry of public health



Source: (Ministry of Public Health, 2019)

There are twenty-nine public hospitals; each is governed by an administration board appointed by the government, they are autonomous at the administrative and financial levels, they sign contracts with financing agencies including the MOPH and are reimbursed as the private hospitals.

The ministry is responsible for the hospital admission and the contractual relation between the ministry and the hospitals whether public or private.

The MOPH is responsible for the regulation of the health system at accreditation, licensing and complains levels. The accreditation is a tool stipulated to enhance the quality and functionality of the hospital services and primary health care network. It is an evaluation system that incentivizes hospitals' development and a prerequisite of the contractual agreement between hospitals and the public funding schemes. However, the accreditation does not apply to private professional or physician's clinic.

MOPH licenses professionals once they register in their respective order or association. Licensing is a tool that evaluates the qualifications of the professionals before being able to practice. The licensing is supported by the professional orders or association, by universities and Ministry of Education and Higher Education who organize the colloquium exams which is a prerequisite to practice in Lebanon. The practice authorization is valid for a lifetime, and it is not subject to renewal or to periodic evaluation. Due to a lack of planning at national level and since the MOPH cannot interfere in the number of professional graduates or applicants the Lebanese healthcare system has an oversupply in human resources mainly physicians and a shortage in nurses. In case violation or medical negligence, the suspect case should be forwarded first to a disciplinary board of the professional association or order before

submission to court. The MOPH is responsible for the final decision (Kosremelli Asmar & Yeretdzian, 2019). It is worth mentioning that the occupational and speech therapists are not entitled to register or to get a license. They start practicing as free lancers after graduation.

The MOPH collects different types of information: demographic and medical information, resources and quality management information, pharmaceuticals usage information and information related to disease and epidemics. It also collects information on preventive, curative, and administrative care. The healthcare providers submit this information on regular basis but with various frequencies (WHO, 2012). Though the variety of information, it lacks integration and it is not combined at any level even at the MOPH, who is the regulator of the healthcare system in Lebanon nor at the Central Administration of Statistics who is “the official body responsible for acquiring and disseminating of information in the country” (WHO, 2012). Data generated by bodies outside the MOPH whether they are financing agents, service providers or researchers; private or public entities; cannot be accessed except through a formal request. The country lacks a national healthcare information system and needs to develop a “unique patient identifier” number and a “unified medical record” accessible across different care levels. Information suffers at two main levels: the availability and accuracy from one side and the compilation and distribution from the other.

As to the patient complains, the MOPH encourages patient to report health incident through the call center or the mobile application (Kosremelli Asmar & Yeretdzian, 2019). Health incidents are sometimes reported on media. Private clinics might not have a complain referee or desk, physician are not obliged to have a liability insurance and a legal case for medical error needs to pass by the order and the MOPH before being presented in front of legal court

and rarely is an action taken against healthcare providers (Kosremelli Asmar & Yeretizian, 2019). While the MOPH has built a complain process inside the hospital.

The role of the Ministry of Social Affairs

The socio-medical healthcare services are under the governance of the Ministry of Social Affairs.

MOSA organizational structure englobes the directorate of social services and that of social development; both refers to the general director. The department of persons with disabilities (PWD) affairs is under the social service directorate.

In addition, MOSA has several projects directly under the supervision of the general director of which two programs are disability oriented. The first program is Right and Access Program that issues the disability card, provides some assistive medical devices, and approves admission to rehabilitation centers. The second program is MOSA Therapy Centre Program that provides speech therapy sessions and cognitive tests. However, some private schools offer socio-medical services for students with disabilities. Schools are under the governance of the Ministry of Education and Higher Education.

Therapists are independent liberal professionals who are not obliged to get a license or to register in an order or syndicate or association.

1.2.2.3.Financing and payment mechanism: a combination of public and private sectors

Financers are a combination of private – public sectors. There are the MOPH, multiple social financing agents, the private insurances and out-of-pocket. Informal payment is prominent in Lebanon.

There are six independent public funds financed by individual compulsory contributions and the national budget (Kosremelli Asmar & Yeretizian, 2019). Two social security funds; the National Social Security Fund (NSSF) covers private sector employees around 28% of the population, the Cooperative of Civil Servants Fund (COOP) covers the public sector employees insures 5% of the population. Three army schemes insuring 9% of the population. Mutual funds for judges, university and schools teaching staff. The voluntary health insurance policies cover 12% of the population. The remaining 46% of the population are partially insured by the MOPH for their hospitalization costs. Vulnerable population like children under 5 years, people with disabilities are covered by the MOSA and the MOPH(WHO, 2019).

All public schemes impose cost-sharing on hospitalization and ambulatory healthcare services (WHO, 2012). These funds cover half of the Lebanese population while the hospitalization cost of the second half of the population is partially covered by the MOPH (Khalife et al., 2017) and its ambulatory and pharmaceutical costs are covered patient out-of-pocket. Out-of-pocket payment has reached 36.4% of total expenditure on health, while the public funds share has been 47.6% and that of voluntary private health insurance 16% (WHO, 2017).

Table 2: Different Public Sector Funds

Public Fund	Tutelage	Beneficiaries	Sources of Funds
National Social Fund	Ministry of Labor	<ul style="list-style-type: none"> •Employees in non-public institutions and their family members •Wages earners and contractual employees in the public sector 	Non-public employers and employees
Civil Servants' Cooperative	the Presidency of the Council of Ministers	Public sector employees and their families	Employees' contribution and government taxes revenues
Army Medical Healthcare	Ministry of Defense	Army members and their families	Taxes revenues
Three different financing funds	Ministry of Interior and Municipalities	Employees and their family members of: <ul style="list-style-type: none"> •General Security Forces •Internal Security Forces •State Security Forces 	Taxes revenues
Customs Employee Fund	Ministry of Finance	Customs employees and their family members	Taxes revenues
Ministry of Public Health Funds	Ministry of Public Health	Uninsured citizens	Taxes revenues

Source: prepared by the author

The scope of coverage differs from one public fund to another and the services are not identical (Kosremelli Asmar & Yeretjian, 2019). For example, the military funds provide 100% coverage for ambulatory and in-patient services while Civil Servant Funds covers 90% of the hospitalization's coverage and 80% of the ambulatory services.

The NSSF, the main health financing scheme, provides its members with 90% of the in-hospitalization bill and 80% of the ambulatory care costs. It excludes dental care from the coverage policy.

Those schemes reimburse the in-hospitalization costs directly to the hospital based on a pre-approval, while the patient pays the ambulatory fees and applies for reimbursement. The repayment is based on a special pricing reference with a delay of one to two months.

The MOPH, being the insurer of last resort, covers 90% of the in-hospitalization fees for uninsured population. For the ambulatory services, the MOPH relies on the national network

of primary healthcare centers. The centers provide basic healthcare services mainly family medicine, obstetrics, dentistry, cardiology, pediatrics and mental health services at reduced cost, and the MOPH support them with free chronic medications, vaccines, essential drugs (WHO, 2017).

The majority of these centers are owned by NGO around 67%, while 20% owned by municipals and 13% governmental under the governance of the Ministry of Public Health or the Ministry of Social Affairs (WHO, 2017).

As to dental care, some public funds cover it while the NSSF excludes it from its coverage.

The public financing schemes cover only the physiotherapy treatment costs for a limited number of sessions per year and based on a defined price list. They exclude speech, psychomotor, psychological, behavioral therapies from their coverage (Yehia et al., 2014). MOSA partially covers these therapies at certain NGOs centers.

There are 52 private insurance companies in Lebanon , they operate under the control of the governance of the Ministry of Commerce (Bankmed, 2017) and cover around 32% of the private and 15% of total health expenditure (Kosremelli Asmar & Yeretizian, 2019). Citizens purchase private insurance for several main reasons: lack of eligibility for employment schemes, need to cover the co-payment and facilitate the approval bureaucratic process.

Mutual funds increase with time and tend to replace private insurance at a lower premium.

The purchasers are mainly liberal professionals like engineers, pharmacists, physicians, and self-employers. The coverage scope varies according to the term of the insurance contracts; policies mainly cover in-hospitalization fees, some extend the plans to cover physiotherapy

treatment, imagery, and laboratory services. Speech, psychomotor, psychological, and behavioral treatment costs are excluded. Dental care is also excluded from the coverage plans.

The out-of-pocket payment is divided into 3 groups: the cost sharing or co-payment, the direct payment, and the informal payment.

All public schemes impose a percentage of cost sharing. The patient pays between 5 and 15% of the hospitalization invoice depending on the funding agency, this percentage reaches 20% of the ambulatory and pharmaceutical fees. These percentages are based on the services' official price list.

Direct payments occur for uncovered interventions, services or goods from the public funding schemes and can be variable through the schemes. It occurs in hospitalization settings in case of esthetic surgery or any new expensive and unproven therapy, or non-authorization by the fund technical committee in case of unjustified prescription or recurrence of certain diagnostic tests or imaging. A classic example is when a recent surgical supply is used before being covered i.e., added to the list of healthcare services / devices adopted by a specific fund. Another example is when a beneficiary receives healthcare services in a hospital not contracted with the health fund. The patient must pay the complete invoice and then submit a claim for reimbursement. As a result, the patient pays as direct payment in every case the funding agency is not covering. In ambulatory care, typical examples are in pharmacy the over the counter (OTC) medications like vitamins, dietetic supplement, in physiotherapy the sessions that exceed the allowed number, also the dietetic consultation, speech therapy and psychotherapy consultations and other health practice not recognized by the fund as eligible health services.

The informal out of pocket payment is widespread and happens in various scenarios, even though there is no studies evaluating its volume and effect (Kosremelli Asmar & Yeretjian, 2019). Patients are sometimes asked to pay extra informal amounts before admission and based on the hospital or physician request. The hospital asks for pre-payment to ensure that the patient settles his share, or because of the outdated pricing lists, or the delays in reimbursement from the public funds or simply because the physician or surgeon demands an extra charge because he or she is not satisfied with the public allowed fees. For example, the NSSF proposes 7 USD per visit in cabinet for a general practitioner and reimburses 80% of that amount to the patient, the physicians find the fees low and charge an informal additional fee.

Public financing agents purchase in-hospitalization and ambulatory services from public and private providers. The MOPH purchases hospitalization services from private and public hospitals for the uninsured citizens almost half of the population . It reimburses hospitalization service of the uninsured patients by a flat rate on surgical procedures, fee-for-service based on detailed bills for non-interventional hospitalization (WHO, 2012). In order to restrict unnecessary admissions and over- prescription and usage of high technological devices; in a market dominated by a supplier-induced demand, the MOPH set a ceiling for each hospital's contract limit (Walid Ammar et al., 2013) and obliged the patient with a co-payment. To be admitted on the expense of the MOPH, the patient has to pass by one of the ministry of health admission offices along with an admission slip dully filled by his or her physician, if the patient does not benefit from any other public funds; the MOPH is not the sole public financing agency; his or her request would be approved, this approval is called "visa" for admission. Upon discharge, the patient settles his co-payment share and the ministry audits the bill and reimburses the hospital. The contract between MOPH and private or public hospitals has a

yearly ceiling based on the population served, the unused funds will not be brought forward to the next year; this financial arrangement motivates hospitals to over hospitalization (Kronfol , 2014).

Other public and private funds also contract with public and private hospitals for in-hospitalization and ambulatory services.

As to the primary services, only the MOPH signs service contracts with the NGOs, some municipalities and Ministry of Social Affairs who own primary healthcare centers.

The payment mechanisms differ between in-hospital services and primary services. The funds whether public or private pay directly to the hospital and the patient is only responsible for the cost sharing percentage given he or she gets the approval of the funding authority. In the primary health care centers, the patient pays a modest fixed rate per service (Kosremelli Asmar & Yeretizian, 2019).

Doctors and therapists are liberal professionals who own their private clinic and contract with private or public hospitals. They are directly paid based on fee-for-service by the patient. Some work on full time basis in centers or NGOs and they are paid fixed salary or based on capitation. The cost of other services such as hearing devices or specialized glasses are partially reimbursed by some public funds. The patient pays the full amount and submits an official request along with supporting documents for reimbursement by the funding agency. The reimbursement is usually delayed for at least one month.

1.2.2.4. Healthcare workforce: as liberal professionals

Healthcare workers are liberal professionals. The medical care practicing requirement differs fundamentally from socio-medical one. Lebanon lacks a national human resources strategy, MOPH regulation techniques as registering, and licensing are downstream thus it is incapable of regulating the type of medical education, the entry to the healthcare system or the geographical distribution of medical premises. Medical schools are autonomous, and they decide on the number of students enrolled and specialties. The physicians should register at the order to practice medicine. There are two Lebanese orders of physicians in Lebanon one in Beirut and the second in Tripoli: The dentists have their own association. The country has an oversupply of specialized doctors while it experiences a significant shortage in nurses for example (Kosremelli Asmar & Yeretizian, 2019).

The situation of the socio-medical professionals like speech, psychomotor, occupational, behavioral therapist is not different from that of the medical professionals in terms of national strategy. In addition, these professions do not need to register at any order, syndicate, or association. The services are out of the financial scope of the funding authorities. There is a lack of information on the profession, its scope, benefits, and costs. They are liberal professionals, they work out of their private clinic, and they are not supposed to provide any information to any syndicate or order or association. There are some initiatives to be assembled under a formal legal body such as association, order, or syndicate.

1.2.2.5. Provision of services: the dominance of the private sector

The provision of services differs between medical and socio-medical services.

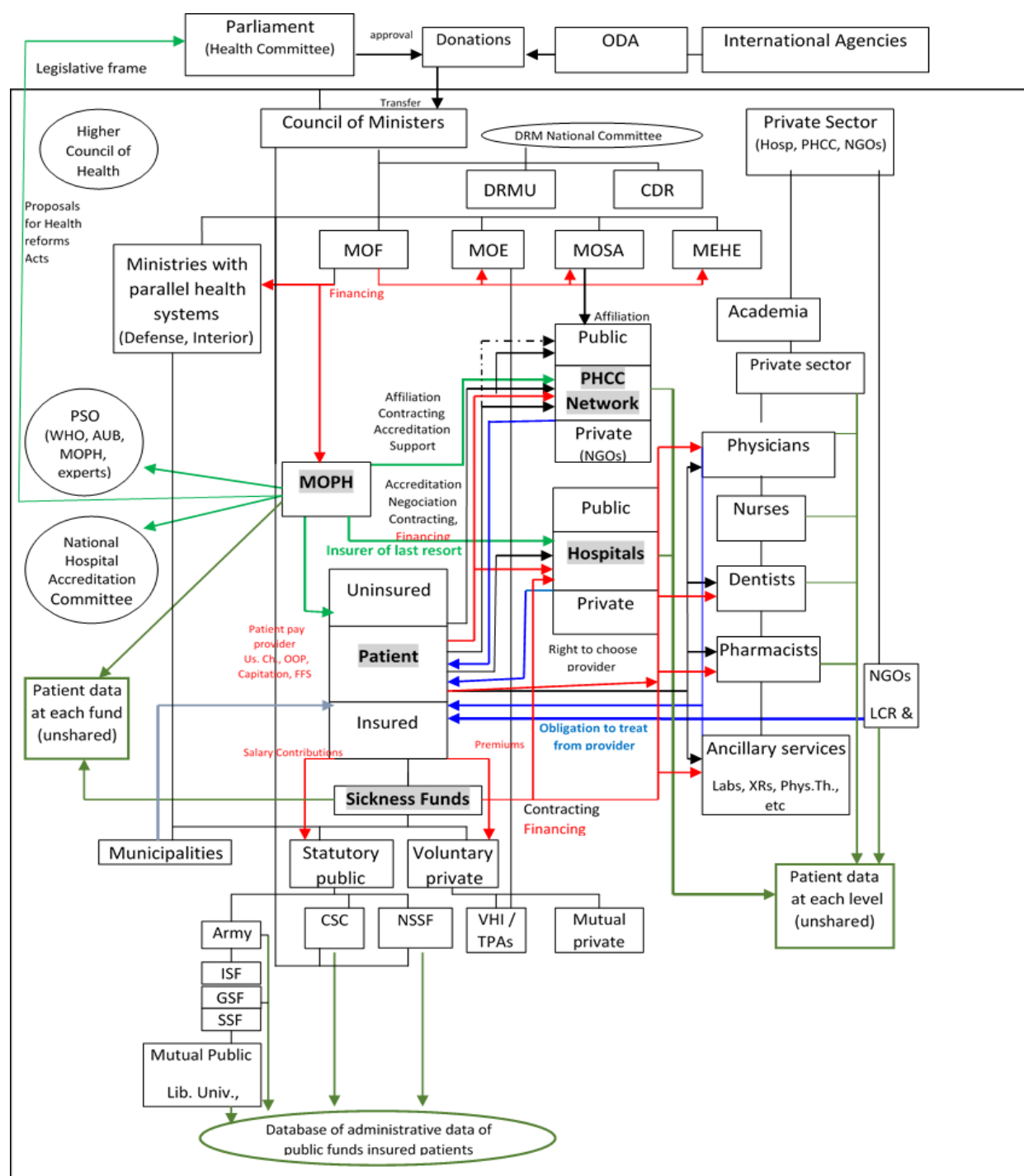
The private sector is the backbone of the medical healthcare system, it dominates the provision of care services, with 80% of the hospitals and 67% of PHC centers (Ammar et al., 2016). Private clinicians, hospital's out-patient departments, health centers not yet part of the national network provide most ambulatory services (Lerberghe et al., 2018). This sector is divided between the for-profit and the non-for-profit agents. The for-profit providers are private hospitals, private clinics and healthcare centers providing services such as laboratory and radiology test. MOPH does not have the exact number of the private clinics present in the country nor their distribution since its role is limited to the issuance of a license to practice (Lerberghe et al., 2018) but most physicians have private clinics and they contract with private hospitals whenever their specialty permits (WHO, 2012). Medical doctors who are employed by public hospitals are allowed to practice in their private clinics and in private hospitals or healthcare centers. The non-for-profit healthcare institutions belong to NGOs, they are mostly healthcare centers, some are long-stay hospitals or rehabilitation units.

The healthcare system relies heavily on the private sector that dominates the service provision (Ammar et al., 2016) and it has an oversupply of hospital beds, technology and physicians, particularly specialists (WHO, 2017).

The private sector maintains most of the socio-medical services although there is no compiled data about the number of speech, psychomotor, occupational, or behavioral therapists. These services are provided either in private clinics or NGOs centers. Some private schools adopt an inclusive program, some NGOs run specialized schools in both cases the needed socio-medical treatment is provided during academic days inside the schools. The providers, in these cases, are schools 'employees.

The ministry provides speech therapy treatment in its center in Beirut. A patient is illegible to benefit after presenting a formal request in the offices of the ministry and getting the ministry doctor's approval. The duration of the treatment is 7 years maximum (Lebanese Republic, 2020).

Figure 4: Overview of the Lebanese Healthcare System



Source (Kosremelli Asmar & Yeretizian, 2019)

1.2.2.6. Patient pathway: unregulated gatekeeper system

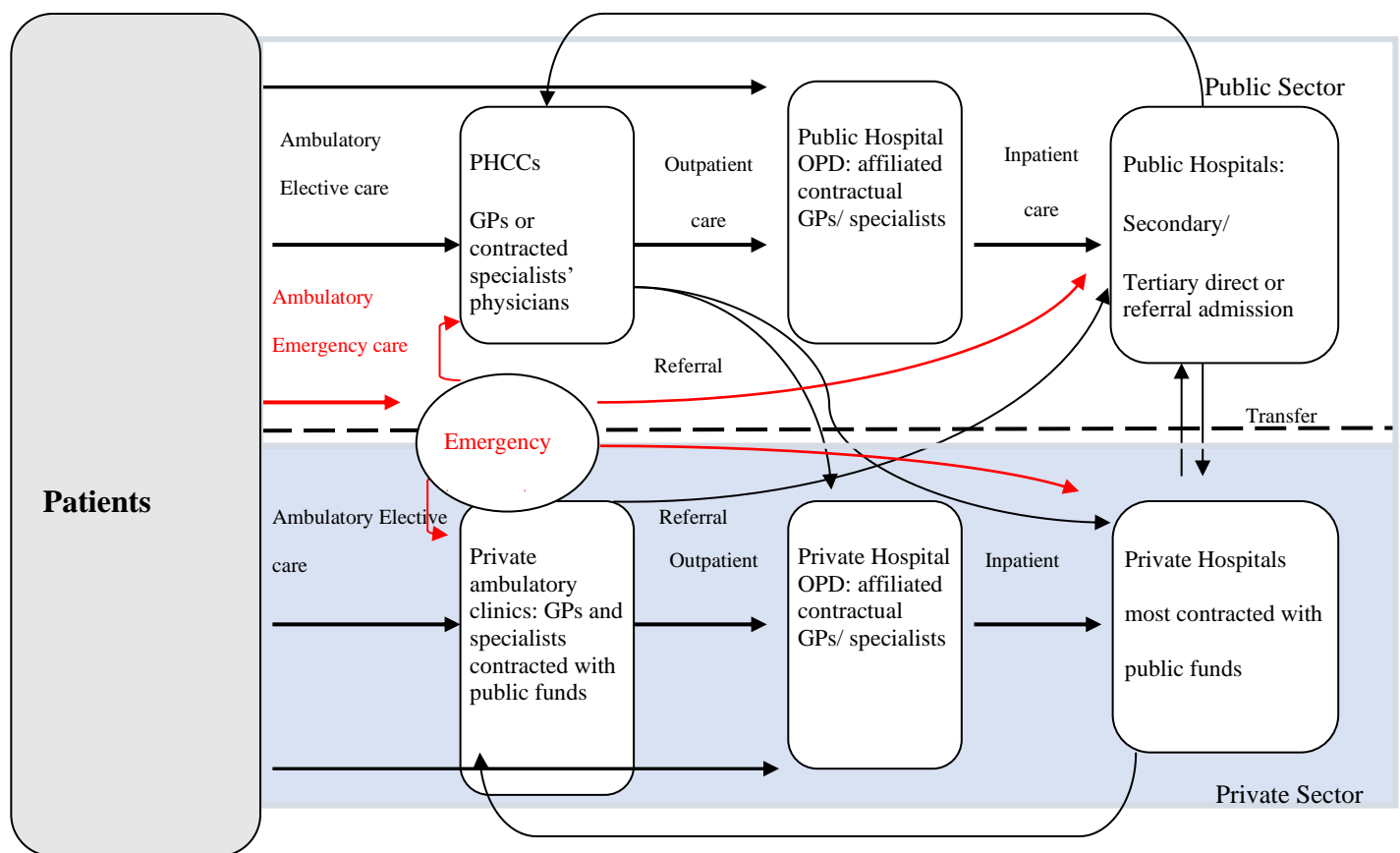
There is no formal or typical patient path through the medical or the socio-medical healthcare system. The system lacks a gate keeper, the patient is free to choose the entry and exit point. The Lebanese healthcare allows the patients to choose a provider, to get a second opinion, to get information about their treatment, and they have the ability to complain. The patient is capable of accessing administrative information such as forms, e-services, legislation, and others on the websites of the health regulator, providers, and payers. However, he or she cannot access information related to the clinical outcome of a certain hospital or physician or center. The patient relies on the reputation of the provider on a word to mouth basis. The same applies to medical errors or complaints.

The patients are free to choose the hospital, the physician, the specialist and to approve a treatment or reject it. Their choices are usually based on their coverage scheme, their financial means, and the urgency of the case. The coverage is related to the professional status of the patient and as previously mentioned. Therefore, some patients choose to purchase complementary coverage mainly a private health insurance in addition to their public.

There is absence of a national regulatory framework for referral and the relation between providers is informal and sometimes absent. The same applies to the relation between primary, secondary, and tertiary care. The patient starts a treatment or seeks a physician of their choice based on the advice of family members, friends, pharmacists, colleagues and regardless of his or her specialty.

Some physicians might informally guide the patient by using their personal and professional networks.

Figure 5: Patient Medical Pathway



Source: (Kosremelli Asmar & Yeretizian, 2019)

To summarize, the system is a fragmented mix of public-private providers and financiers. There is no active referral system linking primary care to secondary, the current referral system is limited to administrative issues related to hospital's admission at the expense of a public fund through a visa center granting permission with an aim to control the bed supply (WHO, 2012). Lebanese healthcare system collects a great amount of information, but this information is fragmented, duplicated, and lacks consistent diffusion to concerned parties (WHO, 2017). The system lacks coordination and/or continuity of care, patient pathways and referral processes (Lerberghe et al., 2018). The consequences of this fragmentation highly affect persons with

disabilities who usually need complex healthcare services that involve medical and socio-medical settings over prolonged period of time.

The following section presents the situation of persons with disabilities in the Lebanese healthcare context.

1.2.3. Persons with Disabilities as representative of patients in a fragmented system

Lebanon is an example of a fragmented profit-oriented care system. Patients who need socio-medical and medical care over a long period of time are the ones most affected by the fragmentation of the system. The discontinuity of care jeopardizes the quality of care and affects the performance and life quality of the patients. Persons born with disabilities are the best representatives of this category because they demand socio-medical and medical care services over their lifetime. Historically, institutional care was the main choice for parents of children with disabilities whether physical or mental (Murphy et al., 2011). Recently, parents tended to care for their children at their homes and in their communities. This transformation brought unanticipated obstacles for the children with disabilities, their families, and communities. These challenges are amplified in the highly fragmented, profit-oriented care system.

Persons with Disabilities constitute around 10 to 15% of the Lebanese population (Combaz, 2018). However, there is systemic a deficiency of provisions services, resources and rights to this population category (Baroud, 2017). This is mainly due to the inaction of the government over several years and the absence of law enforcement (Baroud & Mouheildine, 2018) . In May 2000, the Lebanese government has issued law 220/2000 to secure the rights of PWD which defines person with disability as:

“Person who has a decreased ability or has become unable to perform one or more important daily activities, or to attend to their personal needs on their own, or to participate in social activities on an equal basis with others, or to lead a normal personal and social life according to the current standards of the society, due to a loss or functional impairment, be it physical, sensory or mental, total or partial, permanent or temporary , resulting from a congenital disorder, an acquired condition, or a medical condition that lasted beyond normal medical expectations (ESCWA, 2014)”.

The Lebanese government represented by MOPH and MOSA fully responsible for the medical coverage, hospitalization, and rehabilitation services of the PWD. Lebanese citizens with disability can obtain a disability card issued by MOSA (Lebanese Parliament, 2000) if their disability fit into the narrow disability definition provided by the Law 220/2000 (Combaz, 2018); this card needs to be renewed every five years.

In principle, cardholders are entitled to all kinds of healthcare services: primary, secondary and rehabilitation. They should be fully covered by the relevant ministries MOPH or MOSA (Combaz, 2018), but till date none of the public financing agent allocates a budget for occupational and behavioral care services (Yehia et al., 2014) .Thus, the law 220 is not enforced and PWDs access to healthcare is sometimes denied due to either the scarcity of the rehabilitation services, physical occupational therapies and other services (CRC, 2017).The cost of services is the main barrier to the access of healthcare for the PWDs especially due to the lack of financial coverage for specific healthcare services (Baroud & Mouheildine, 2018), the physical environment of the healthcare buildings public or private that do not meet the inclusive standards, and the lack of information about available services. Stade at al. (2017)

cited that even MOSA does not have adequate information about services available to refer persons with disabilities.

The Lebanese government does not provide financial support service to the PWDs or their families (CRC, 2017), consequently, the family or one of its members would be the main caregiver. Usually, the mothers are the ones who seek support and services (Combaz, 2018), the absence of “an effective social protection system” makes the financing of all social care on behalf of the family or non-governmental institutions (Solidar, 2015). This situation aggravates the current crisis.

1.3. An interpretative posture that gives voice to the parents of children with disabilities

This section presents the epistemological and methodological foundation of our research. We will present first our interpretativist phenomenological approach, then we will explain the methodological choices made to study the challenges faced by parents of children with disabilities in a highly fragmented healthcare system. Finally, we will present a set of data collection and data analysis methodological choices considering the need to increase the reliability and validity of our work.

1.3.1. An interpretativist phenomenological approach

Our research follows an interpretativist phenomenological approach which allows to investigate persons' lived experiences and to explore how they are making sense of these experiences (Smith & Osborn, 2003, 2015). Phenomenology permits the researcher to focus on common and not individual experiences lived by the participants when facing a phenomenon such as dealing with disability in a highly fragmented healthcare system (Creswell, 2007).

It is an approach that combines the interpretative and the phenomenological commitments. The interpretative paradigm allows to contextualize and “make sense” of the participants' experiences, while the phenomenological approach gives voice to the participants (Larkin et al., 2006). It postulates that the values and beliefs of the researchers guide the collection, interpretation, and analysis of the data (Ryan, 2018a). This approach considers knowledge as subjective and based on people's experiences and understandings of them (Ryan, 2018a; Snape & Spencer, 2003). According to interpretivists, there is no single reality that exists

independently from our senses, instead there are multiple socially created realities. External reality is affected by the concepts and backgrounds of the observers (Rehman & Alharthi, 2016; Ryan, 2018b). As Flick and al. (2004, p. 89) state that perception is not a passive – receptive process of representation but it is an active constructive process of production”. Interpretivism helps to understand the interpretations of individuals about a specific social phenomena (Rehman & Alharthi, 2016). The phenomenological approach allows to examine the participants’ subjective experiences (Lopez & Willis, 2004) rather than the experiences prescribed by pre-existing theoretical preconceptions (Smith & Osborn, 2015). The interpretative phenomenological approach adopted is most suitable for our research since it provides us a clear understanding of how the participants perceived their personal challenges through their own terms. It allowed the parents of children with disabilities to express themselves and their lived stories the way they saw fit.

Our interpretativist phenomenological approach being now presented, we try in the following section to answer the fundamental question: “how to approach this reality?” Our answer favors research strategy that considers the interdependence between our subject and object. Our main objective is to understand in-depth the challenges faced by parents of children with disabilities in a highly fragmented healthcare system. Consequently, our approach is exploratory, it starts as inductive and then turns into abductive.

1.3.2. An inductive and abductive research strategy

The choice of methodology is not neutral, it depends on the objective of the research (Charreire-Petit & Durieux, 2014, pp. 57–80). For an exploratory objective, a inductive and/ or abductive approach is privileged.

Our research approach is hybrid, it uses both inductive and abductive approaches. It is characterized by frequent going back and forth between the mobilized theories and the empirical data.

We started our research by considering elements that emerged from our first literature review. This allowed us to orient our conceptual framework and the way to approach the field. It also allowed us to identify preliminary gaps related to our research. Our going back and forth between the field and the theory permitted us to refine and enrich our conceptual categories. The emergence of new elements such as compassion for example pushed us to explore new theoretical fields.

1.3.3. Access to the field

Our thesis uses a qualitative methodology which allows us to understand the phenomena being studied. The following parts detail the strategy used to attain our objective. We first justify our choice of qualitative approach, then we define our unit and period of analysis as well as the choice of our sample.

1.3.3.1. Qualitative method serving as exploratory purpose

Prior studies on healthcare fragmentation have mostly focused on the provider and financier perspectives (Agha et al., 2017; Cebul et al., 2008; Elhauge, 2010; Mossialos et al., 2005; Robben et al., 2012; Sipido et al., 2020; Siqueira et al., 2021; Stange, 2009), we decided to study this fragmentation from the parents' perspective. Qualitative strategies suit our research best because they allow an in-depth understanding of challenges faced by the parents in a highly fragmented system. Qualitative studies empower the individuals to share their feelings and

stories, they allow the research to hear the voice of the participants (Creswell, 2007). Denzin and Lincoln (2005, p.3), cited by Creswell (2007), define qualitative research as “a situated activity that locates the observer in the world. It consists of a set of interpretive material, practices that make the world visible. [...] this means that qualitative research study things in their natural settings, attempting to make sense of, or to interpret phenomena in terms of the meaning people bring to them.”

Contrary to quantitative studies, qualitative research stresses the socially constructed nature of reality, the intimate relationship between the researcher and what is studied and the situational constraints that shape inquiry. In contrast, quantitative studies emphasize the measurement and analysis of causal relationships between variables, not processes.” (Wacheux, 1996)

We started with an exploratory qualitative study to understand the challenges as experienced by the patient using a highly fragmented healthcare system. This allowed us to focus on the participants’ lived experiences in natural settings. They are the most suitable research methods for discovering the meanings and perceptions that the participants give to specific events, structures, and processes such as what they experienced and how they experienced them.

This allowed us to dive deeply into the problem and grasp the phenomenon under study from a perspective of the meaning for the individuals themselves (Wacheux, 1996). It permitted us to identify a phenomenon as dealing with highly fragmented systems, we then collected data from the parents who experienced this phenomenon and developed a description of its essence. This description answers our question of “what” are the challenges and “how” the participants experienced them (Creswell, 2007).

Based on the above, it seems that our research topic requires qualitative methodologies.

1.3.3.2. Research process

Our strategy, as previously mentioned, is characterized by going back and forth between the field and literature.

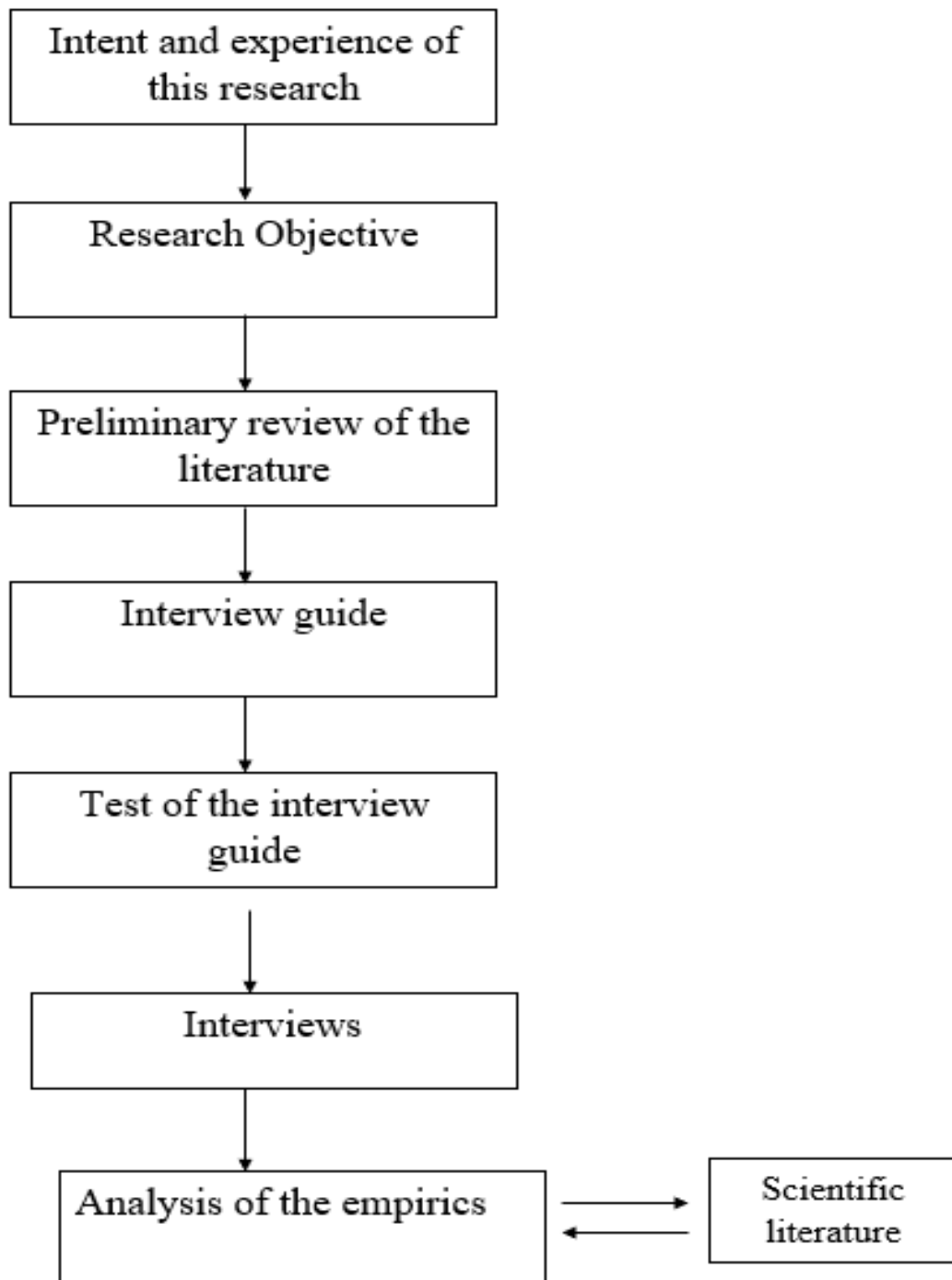
By contrast with hypothetico-deductive research that starts with a literature review, it is the social relevance of the topic that was the driver of this work. As a parent of a child born with disabilities, I experienced the challenges of the Lebanese highly fragmented healthcare and later in my position as a researcher I was driven by my scientific curiosity to study this phenomenon in depth and capture the perspective of other parents experiencing similar situations.

Apart from this personal life experience, our formal work started in February 2016 by a broad literature review on healthcare fragmentation, healthcare system, integrated care. From this work we defined our problem around the challenges faced by parents of children with disabilities in a highly fragmented system, and we elaborated our interview guide. Field work started in 2017 by pre-testing of the guide through two exploratory interviews. Based on which, the guide was amended to include the emergent ideas. The pretest also allowed us to better understand the reality of the field, to identify the potential participants, the nature of the data to collect as well as the potential problems that might be encountered.

During the entire work, we faced several challenges because of the country's context which experienced a social, technical, economic, financial, political collapse and security issues. We, however, did our best to continue our research work.

Data collection required from the research to be available and very flexible to align with the participants preferences regarding timing and setting. Our sample included twenty-nine interviews with parents of children with disabilities. The total number of hours of interviews is nineteen hours with an average of thirty-nine minutes per interview.

Figure 6 : Research Process



1.3.3.3.Sampling strategy

Having chosen a phenomenological strategy, we adopted a purposive and selective sampling to recruit the participants so as to ensure that they can provide in-depth and detailed information about the phenomenon being studied.

We therefore identified criteria on which we based our selection of participants. The most prominent criterion being the participant's experience with the phenomenon under study. We looked for participants who have shared an experience but vary in characteristics and in their individual experiences. The inclusion criteria were: 1-to be the parent of a child born with a disability, 2- the disability has been discovered either at birth or at early childhood, 3-the person with disabilities has reached minimum ten years old to ensure that the family has sufficient experience of caring for a person with disability.

We made sure that our sample covered different types of disabilities and coverage schemes to grasp a wider range of challenges experienced. The participants had different coverage schemes: seven participants had a mix of public fund coverage scheme and out of pockets expenditures, ten had a combination of public fund , private insurance and out of pockets, seven participants has a combination of private insurance and out of pockets, three participants depended on out of pocket expenditure, two participants relied solely on a public fund schemes.

Table 3 below presents the coverage schemes of each participant.

Table 3: Coverage schemes of the participants

Coverage Schemes	Participants
Public Fund and Out of Pockets	4
	9
	14
	18
	21
	22
	26
Public Fund-Private Insurance and Out of Pockets	1
	2
	5
	6
	8
	11
	15
	16
	23
Private Insurance and Out of Pockets	28
	3
	7
	10
	12
	25
	27
Out of Pockets	29
	13
	19
Public Fund	20
	17
	24

Source: prepared by the author

We approached 45 families of persons born with disabilities and living in Lebanon, 29 parents approved to share their experience for the purpose of this study. To have a holistic perspective on the experiences of the parents of children born with disabilities we intended to include persons with various types of disabilities. The participants chosen were divided as

follows: 7 participants who have a child with down syndrome, 4 with autism, 3 with cerebral palsy, 4 with mobility disability, one with hearing, one with vision disability, and 8 with different types of developmental disabilities. Table 4 below presents the type of disabilities of the participants children.

Table 4 : Types of disabilities of the children of the participants

Participant	Disability
6	Down Syndrome
7	Down Syndrome
11	Down Syndrome
13	Down Syndrome
14	Down Syndrome
16	Down Syndrome
21	Down Syndrome
10	Autism
19	Autism
23	Autism
28	Autism
3	Cerebral Palsy
12	Cerebral Palsy
26	Cerebral Palsy
1	Mobility
4	Mobility
9	Mobility
24	Mobility
15	Hearing
22	Vision
5	Developmental
8	Developmental
17	Developmental
18	Developmental
20	Developmental
25	Developmental
27	Developmental
29	Developmental

Source: prepared by the author

1.3.3.4. Data collection procedure

Data was collected through semi-structured interviews with parents of children with disabilities. Most of the interviews were conducted face to face, however, because of Covid-19 we were obliged to conduct some of them through online methods. Semi-structure interviews allow the participant to share experience freely but guided by specific questions from the researcher. This constitutes the major source of our data. All our twenty-nine interviews were semi-structured.

All parents had been contacted personally by the researcher to schedule an interview based on their preferences. The interviews were based on the guide elaborated by the researcher and pretested by two exploratory interviews with two parents of children with disabilities, one had a child born with mobility disability and the second had a child with developmental disability. Based on these interviews, we prepared an interview guide with open-ended questions to help the participants to delve deeper into topics that they consider important. The interview guide was divided into three sections: the socio-demographic information, the services needed, their financing details and the social context. This allowed a thorough understanding of the context and its influence on the experience of the parents.

The interviews had an average duration of thirty-nine minutes. The interviews were audio-recorded after getting the oral consent of the participants. All the interviews were conducted by the author in spoken Arabic (Lebanese mixed with French and English expressions). The interview guide was used to ensure that all topics were covered, it was further elaborated when new themes emerged during the interviews.

The interview was based on preliminary literature review .It was prepared in English and were translated to Arabic using back translation (Haccoun, 1987). The Arabic versions were tested to ensure clarity and no changes were needed after the pilot test. The interviews were transcribed verbatim in Arabic and the transcript were shared with some of the interviewees for validation (Noble & Smith, 2015).

Table 5: Semi-structured interview guide for exploring the challenges of the healthcare as perceived by the parents of persons with disabilities

Theme or Category	Questions
Socio-demographic data	<ol style="list-style-type: none"> 1. Family Composition 2. Number of children in the family 3. Educational level of the parents (mother /father) 4. Employment status of the parent (mother/father) 5. Age of the person with disabilities 6. Child with disability birth Order? 7. Type of disability 8. Child Condition 9. Current Treatment 10. Educational level of the child with disability / School 11. Present occupation of the PWD (student in a school or an institution/free-lancer/unemployed ...)
Healthcare Services Needed	<ol style="list-style-type: none"> 12. Pregnancy of the mother 13. Delivery 14. Birth 15. Tell me about the day when he/she was born 16. How did you discover the disability? Who told you? 17. Can you describe that day? 18. Age the disability has been recognized 19. What type of care was/is needed? 20. Medical: can you elaborate? Regular, surgery, 21. At what age did they start? 22. Till what age? 23. Was it the same provider? Or many? 24. Socio-medical: What type of social care (speech therapy- psychomotor orthopedagogue – physiotherapy-rehabilitation) were /are needed? 25. At which age did they start? 26. Until what age? 27. Was it the same provider? Or many? 28. Can you describe the relation between the different providers (among themselves: physician and social professionals)?
Financing	<ol style="list-style-type: none"> 29. How did you finance this care path? Medical and Social <ol style="list-style-type: none"> a. Do you have insurance, or the services are privately financed, or have you received any other support? b. Have you used the ministry of Health services or coverage? if yes for what type of treatment? c. Those of the Ministry of Social Affairs? 2. Do you have an estimate on how much each of these services cost? 3. Was there any special incident or situation related to the financing of these services that you would like to share with us?
Social Themes	
Parent Couple	<ol style="list-style-type: none"> 30. Can you describe your role as a parent? Finance-Knowledge—Advocate-Coordination between the social and medical care providers? 31. How do describe your knowledge regarding the case of your kid

Parent Network	32. Who oriented you to the physician? Other service providers? 33. How did you know about these services? 34. In case, there are social providers: who referred the family to the providers? 35. Can you describe the role of your extended family, friends, neighbors, colleagues in the care path of your kid? 36. Do know another family who has a child /youth having disabilities?
Key Physician/ Service Provider	37. Do you refer to a specific physician for advice? 38. If yes, can you describe who? why? when? how? since when? 39. Can you describe his characteristics?

Source: prepared by the author

1.3.3.5. Analysis of the empirics

Our coding method is coherent with our methodological approach: it is a mixed method based on both the literature and the data emergent from the field. Our codes were not static and evolved with the analysis.

We conducted a thematic analysis to identify key themes and patterns (Saunders et al., 2015). We started the analysis with an inductive open-coding approach since we were exploring the phenomenon. This approach allowed the research findings to emerge from the dominant or frequent themes inherent in raw data without being restrained by the structured methodologies (Thomas, 2003). We coded using Nvivo 11 software; then we grouped the codes into the themes that merged from the verbatim.

Our first order of codes consisted of two categories: the first one included twelve subcodes and the second one, five subcode. Table 6 below details these categories

Table 6: First order codes: Problems and solutions

Problems	Concealing the bad news
	Incomplete information and medical jargon
	Parents perceived as a goose with golden eggs
	Parent's voice muted
	Lack of support units
	Informational discontinuity
	Geographical scattering of healthcare professionals
	Relational discontinuity
	Scarcity of some assistive devices and services
	Bureaucracy Burden
	Financial Burden / Rigid ceiling
	Financial Burden / Exclusion of services and assistive devices from the coverage
Solutions	Build on prior knowledge
	Seek relevant knowledge
	Mobilize network
	Become the decision maker
	Create organizational solution

Source: Author's compilation

Being in an abductive approach, we noticed that the subcodes are distributed over different levels. The problems are related to three categories: 1-the challenges in the parent-provider interaction, 2-the challenges in the patient care path and 3-the challenges related to the system coverage structure. Thus, we have grouped the challenges under these three themes under the problems code. While the solutions codes are divided into two categories. The individual solutions and the collective success stories. Individual solutions are the solutions adapted by the individual to solve the problems created by the fragmented healthcare system. The collective success stories are solutions created by some participants inside hosting organizations. Table 7 below presents the codes identified at this level of analysis.

Table 7: Second order code

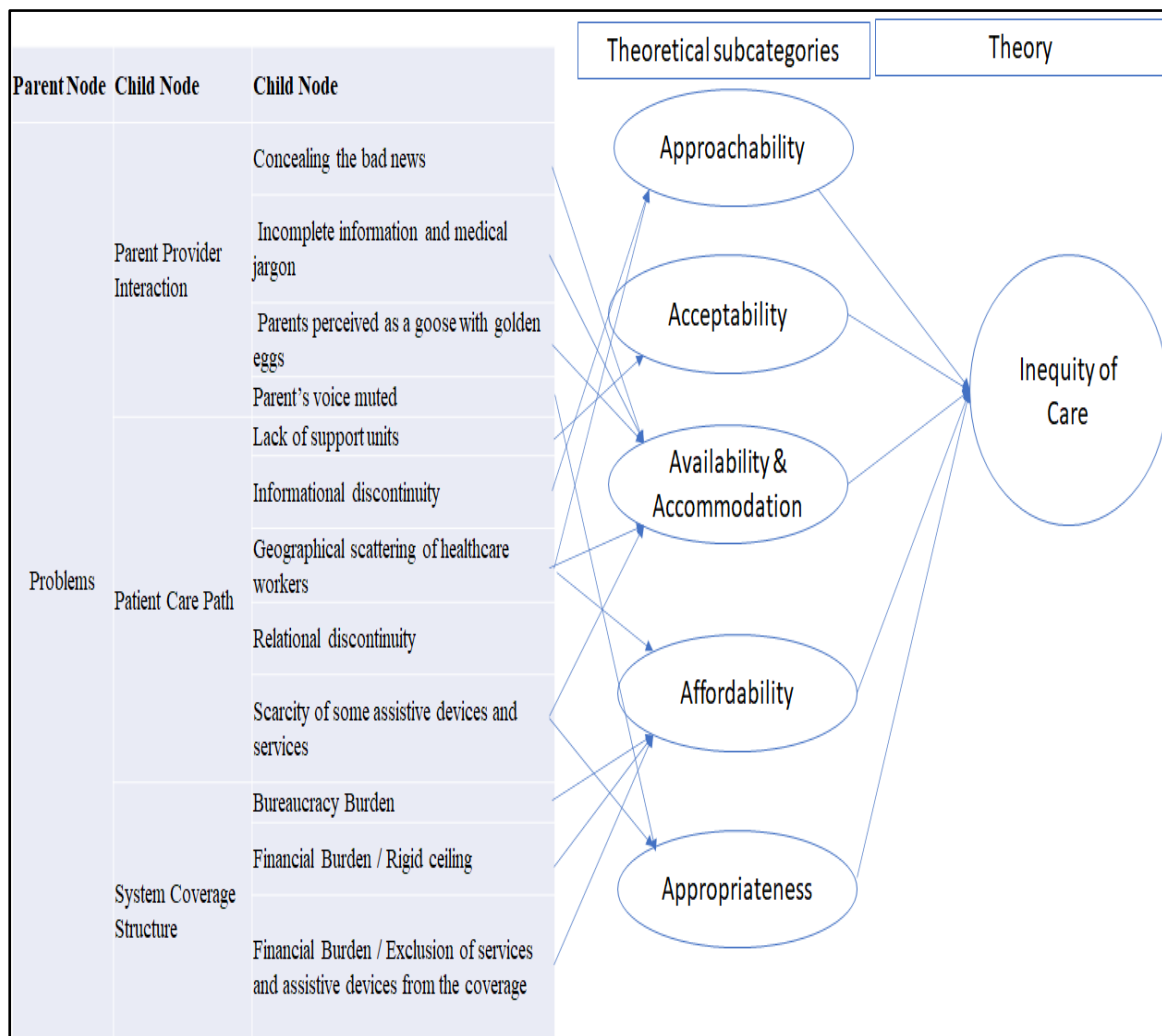
Code level 1	Code Level 2	Code level 3
Problems	Parent Provider Interaction	Concealing the bad news
		Incomplete information and medical jargon
		Parents perceived as a goose with golden eggs
		Parent’s voice muted
	Patient Care Path	Lack of support units
		Informational discontinuity
		Geographical scattering of healthcare professionals
		Relational discontinuity
		Scarcity of some assistive devices and services
	System Coverage Structure	Bureaucracy Burden
Financial Burden / Rigid ceiling		
Financial Burden / Exclusion of services and assistive devices from the coverage		
Solutions	Individual level	Build on prior knowledge
		Seek relevant knowledge
		Mobilize network
		Become the decision maker
	Collective success stories	Create organizational solution

Source: Author's compilation

The abductive approach adopted allowed us to refine the codes. New themes emerged from the empirical data, we were inspired by existing organizational frameworks such as inequity of care, compassion organizing, resilience, and knowledge brokering frameworks.

In the following, we present two models that explain the analysis process that we applied during this work. The going back and forth between the empirical data and the literature permitted us to identify new themes as for example themes related to the inequity of care. We chose to refer to Levesque et al. (2013) inequity of care framework and analyzed our results through the lens of this framework. Figure 7 summarizes this analysis process.

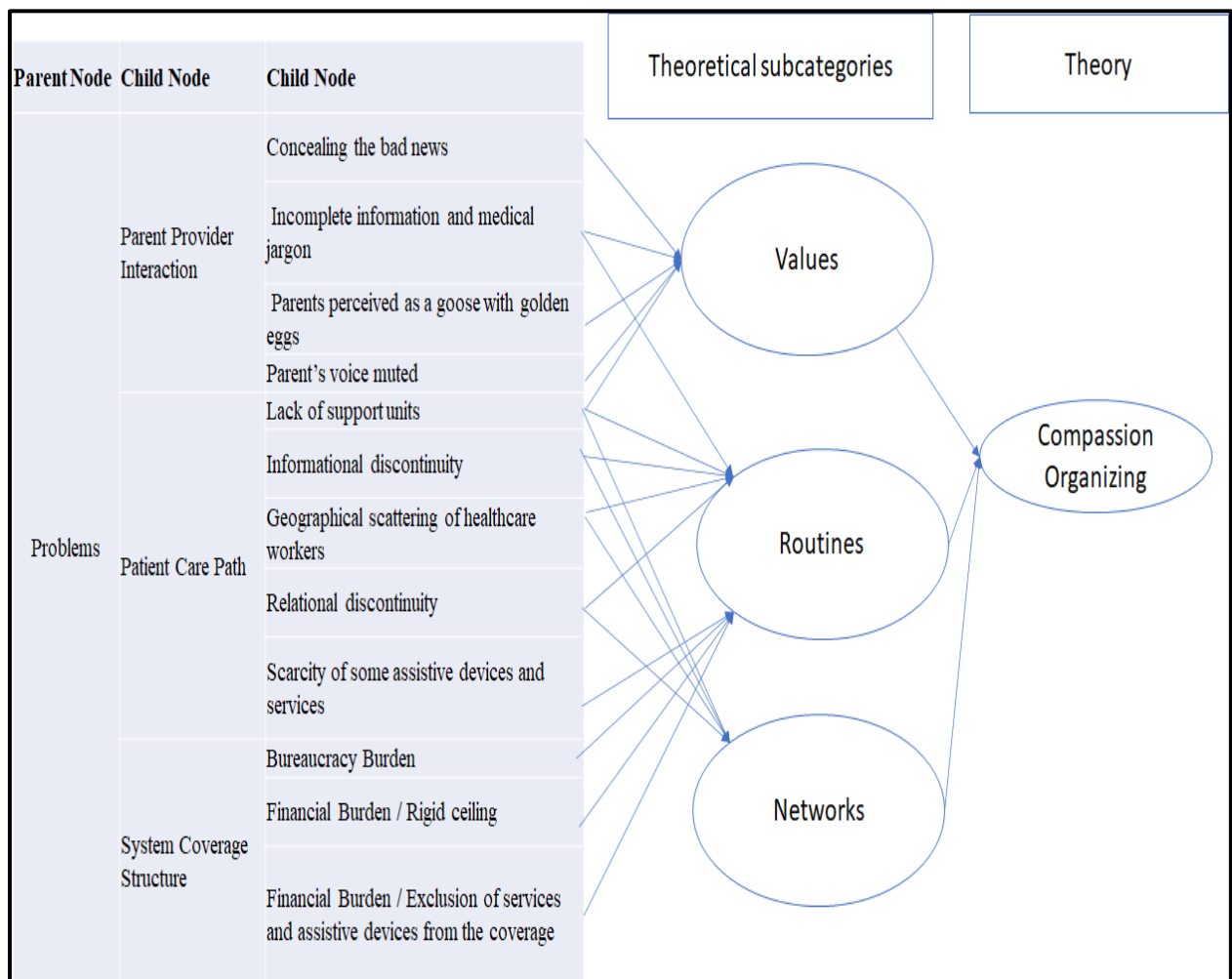
Figure 7: Data Analysis from open coding to inequity of care theory categories



Source: Prepared by the author inspired from (Shepherd & Williams, 2014)

Another example was emergent themes related to Dutton's et al. (2006) compassion organizing framework. We followed the standard process which is presented in figure 8 below.

Figure 8: Data Analysis from open coding to Dutton's et al. (2006) compassion organizing theory



Source : Prepared by the author inspired from (Shepherd & Williams, 2014)

The analysis and the interpretation of the results are related to the coding work. We started with a first level of coding where we identified emergent codes, then at a second level of coding we were inspired by organizational framework.

We proceeded by looking at common experiences lived by the participants to understand the essence of the phenomenon.

1.3.3.6.Validity and reliability

Our research is based on qualitative data collected from semi-structured interviews. Through our work, we tried to ensure the validity and reliability of the study in order to ensure its scientific value.

Validity in qualitative research is related to the data collection and validation techniques. It also refers to the ability of the researcher to perform careful recording and ongoing verification of the data (Cypress, 2017). It is related to the application of proper methodology, sampling process, data analysis and conclusion of the research (Thakur, 2020). Creswell (2007) identifies several strategies to ensure validity of qualitative research among which are the peer review and triangulation. Our results have been presented in scientific colloques and we have also confronted them against scientific literature.

Reliability in qualitative research refers to the consistency of the measure , to the stability of codes (Creswell, 2007, p. 209). We recorded our interviews, transcribed them, and listed the codes in order as a reliability enhancement strategy. With respect to our research, we have conducted a pretest of our guide prior to conducting the interviews to assure the reliability of the guide (Drucker-Godard et al., 1999) . This improved the data collection tool as well as the analysis by ensuring that all the interviewees understood the questions in the same way.

Summary of chapter 1

The Lebanese healthcare pluralistic system is constituted by two interrelated parties: the public and the private. The latter is divided between the non-for profit and the for-profit (Asmar, 2011). The non-for-profit private sector includes primary healthcare centers, nursing,

and rehabilitation institutions. The non-governmental organizations run this part. The for-profit private sector includes private hospitals, private clinics, outpatient diagnosis centers as laboratory and radiology centers. The financiers and providers are a mix of private, public, and public-private combinations. The system, as a whole, is highly fragmented. The government is a regulator body but the true influencer is the non-public sector; the main financier is the government and the main service provider is the non-public sector (WHO, 2012a).

The system includes several public funds agencies in addition to the MOPH, they purchase services from public and private providers. The sources of funds are either governmental budgets or donations or loans from international development partners as World Bank, European Union, World Health Organizations, embassies (Ayoub & Mahdi, 2018)

It relies heavily on liberal professionals and private providers who compete with each other. The fee-for-service payment mechanism rewards the providers for the volume of services and not the quality of the service (Korda & Eldridge, 2011). The system lacks a unified information system and coordination among care units.

The Lebanese healthcare system is a perfect representative of a highly fragmented profit-oriented system with multiple governing bodies having limited authorities.

This fragmentation especially affects persons with disabilities who need multiple care services over long periods of time. To analyze these challenges and to study the lived experiences of parents of children born with disabilities, we adopted a phenomenological interpretative approach. We conducted qualitative research that started with an inductive approach and then shifted to an abductive one.

The elements that we have presented in this section help to provide a better exposure of the process we followed through the thesis. With this section on epistemology and methodology we conclude our first chapter. Chapter 2 and 3 will analyze the gaps and failures resulting from the highly fragmented healthcare system.

Chapter 2- From non-compassion to fulfilling the gaps by embracing roles

his chapter objectivizes the failures of a highly fragmented healthcare system in providing the required services to the users in the case of children with disabilities in Lebanon. It is divided into three sections. Section 2.1. presents the challenges related to the interaction between the patient and the provider. Section 2.2. illustrates the difficulties faced by the patient during the care path. Section 2.3 concretizes the obstacles related to the healthcare policy and system structure. In these sections, we will aim to answer the following questions:

1. What is the main burden experienced by the parents facing the fragmented Lebanese healthcare system? `
2. What are the problems referring to the interaction between the parents and the professionals?
3. What lessons on the structure of the system can be drawn from these experiences?

2.1.Parent-provider interaction through the parent’s eye

The first contact between the parent and the care providers is at the moment of the diagnosis of the child’s case. The quality of these interactions could facilitate the care path or could jeopardize the care outcome (Keen, 2007) and they impact as well the parent’s satisfaction or dissatisfaction with the quality of care they receive. The purpose of this section is to shed light on how the parents perceive their relationship with the care providers.

Our analysis led to the identification of five main points related to the interaction between parents and care providers. These are 1-concealing the bad news, 2-incomplete information and medical jargon, 3-not false hope but encouragement, 4-parents as a goose with golden eggs and 5-parent’s voice muted.

2.1.1. Concealing the bad news

Parents mentioned that it was not the healthcare professionals who informed them about the diagnosis of their child. As such, they consider that the healthcare professionals did not take the responsibility of sharing the medical information of their child. Most of the participants got to know about the disability of their children by chance. For example, a mother heard by accident a conversation between two nurses.

“While I was entering the newborn yard to breastfeed my son, I heard one nurse telling her colleague that my son is down syndrome.” (Participant 6)

Another parent received the news erroneously from a friend.

“After I recovered from the anesthesia, my husband was next to me smiling, I asked to see my baby, he replied that since I had a cesarean section, they (the nurses) won’t bring the baby now. Everything seemed so normal...The second day; I asked to see my child, and I got the same reply. Later, that day, a friend visited me. She embraced me, she started crying and she told me that she was sad to hear about my son. “Is he really paralyzed? she asked I answered yes, as if I knew, and I started to get information from her... Once she left, I cried and cried, my husband came and saw me in this situation.... he started to calm me saying that our son will be fine, he will have an operation and he will be fine...He accompanied me to see my son for the first time...I left the room and challenges of life started.” (Participant 9)

Some physicians tried to delegate the task of announcing the diagnosis of the disability to members of the parents’ families. For example, a physician wanted to inform the grandparents of the child and not his mother. He left a message with the parent asking the grandparents to pass by his clinic. The mother asked him to tell her the cause of his request. At first, he was reluctant to explain but as she insisted, he informed her that her daughter was diagnosed with Down Syndrome. Consequently, the mother was in shock to the extent that she could not understand what he was trying to tell her.

“My husband was out of town. The pediatrician wanted to inform my parents about the disability of my child. I told him that I am responsible for my daughter, so you must tell me and not my parents. First, he was reluctant, but I insisted on knowing.” (Participant 7)

Some participants perceived this attitude as an attempt to hide information from them while others expressed their dissatisfaction to the care provider. As one mother confronted the healthcare professionals when she knew by chance that her daughter had Down Syndrome.

“You do not have the right to hold such an information from me, I am her mother and I need to know. If my daughter is trismic; it is not your fault, and I need to know it.”
(Participant 11).

2.1.2. Incomplete information and medical jargon

Information sharing seems to be an important element in dealing with the disability situation of the child and is considered by the parents a basic requirement as well as a support for them. In addition, the terminologies used in the sharing of information is also an important element to consider as it influences the degree of comprehension and understanding. We will be sharing below the perspectives of the parents and their experiences regarding those two elements.

Parents were convinced that the providers were holding back information about the disability of their child or the treatment plan. One mother complained about this behavior.

“You need to beg the physician, yes and no, to tell, tell me what to expect...At birth, the physicians told me she needs an operation, and I thought it would be done then all would be fine”. (Participant 16)

A parent was persuaded that the physician “*won’t tell the truth.*”

“We discovered the consequences with time. Anyway, the physician will not tell you the truth ...you start dealing with the case and you discover with time that there is no hope.
(Participant 26)

Moreover, parents consider that the healthcare providers did not give them enough information and indication on the consequences of their child’s situation and its impact on the child’s life, nor on his/her expected performance. The parents did not know what to expect, what were the possible delays or complications caused by the disability. A parent described her disappointment when her newly born baby was discharged from the hospital and the physicians did not provide her with enough information about what to expect.

“At birth, he weighed 925 grams, his weight dropped to 840 grams after birth very very tinny baby, 34 cm... (Laughing) I do not know if “this” is called a baby. (A deep breath) The first two weeks he was at risk, we did not know if he would survive... when he was discharged (slow rhythm now) nobody told me ...they told me that there is a delay... Nobody told me that “You” might have delay in walking, maybe mentally, maybe in comportment, maybe in speech They gave us this baby and they have all withdrawn!!!... nobody, nobody told me anything or where I was to expect; where I was heading or what would happen”. (Participant 3)

Because of this lack of information, some parents had high expectations and even thought their child would turn normal after a treatment as explained by one mother:

“I didn’t realize how severe the case was. I thought that if I followed the instructions and my son took his medicines on time, he should be cured and become normal. I dedicated myself. At the age of 4 months, he could not sit at 8 months even, he could

not sit, so I started to consult physicians, they started to pass the idea that he might not be normal". (Participant 27).

When the physicians shared information, they used medical jargon or technical terms which are often not understood by the parents. One parent explained that at the discharge of the newborn child, she got a medical report, but she could not understand a word of the content. Moreover, the latter was not explained to her.

"The case is Chondrodystrophia calcificans congenital, recessive type. Absence of Rhizomelia, Torticollis. The doctors did not explain what these words meant in practice...I remember spending nights on my computer surfing the internet for the meaning of these medical terms and the symptoms of these diseases or syndrome. Even today, when I look back at this report, I feel confused. A million questions, not a single answer..." (Participant 1).

2.1.3. False hope versus encouragement

The tension between hope and the reality of a situation presents a communicative paradox in the context of disability. Parents, when faced with unexpected news of disability, rely highly on hope and encouragement from their surroundings to be able to cope with the situation. Healthcare professionals are perceived by parents as having to play a supportive role. However, some of the participants expressed their distress from the "negative comments" of the provider.

"We had lots of negative expectation from the experts: "Do not imagine that he could walk one day, that he would play one day...." Do not put the hope so high. At this stage,

faced with all the negative feedback, we decided that we need to educate ourselves on the case. (Participant 2)

A mother “cried a lot” when the doctor estimated that her son would die at the age of 7 years.

"Professor L (she still recalls the full name) told me exactly, things that hurt remain forever, we might forget nice comments, but you will never forget what hurt you, he said “your son is paralyzed, he won’t be able to control his urinary or bowel system and he would die at 7 years old. I replied by yes....and I cried a lot.”(Participant 9)

Another mother collapsed at the orthopedic clinic when the physician announced in a factual manner that her son might die soon without making sure first that the parents were aware of the seriousness of their child disease.

"We visited an orthopedic who had been practicing for long time in a very well-known university hospital in Beirut. At that time, my son was 10 days old. The doctor examined him and could not figure out a diagnosis, so he got a book from the shelf behind him, then called a colleague into the clinic. After a while, he looked at my husband and me and said in a firm and confident voice “if your boy survives; bring him back to reassess the case”. Until that moment, I was not aware that my son had a high mortality risk. I collapsed”. (Participant 1)

2.1.4. Parents perceived as “a goose with golden eggs”

In a highly fragmented profit-oriented system, with minimal coverage and high out-of-pocket disbursements, parents perceive themselves as funders for healthcare providers.

The parents expressed their disappointment of the professionals' behavior. They perceive them as “greedy” and “materialistic”.

“The pediatrician was greedy. He used to charge more than he charged my sister because I had insurance, and my husband was working as expat.” (Participant 7)

“They were materialistic...Unfortunately!... They were not compassionate ... my son paid the price...he did not improve. I am talking from a burned heart.” (Participant 25)

Some parents felt that the physicians would not provide them with information unless they paid for it.

“I feel that you are not helped ...unless you pay a fortune, you are not able to find someone that gives you information. It is catastrophic, I suffer I cannot tell you how much. You need to beg the physician who hesitates saying yes and no, you need to beg him or her to tell, tell me what to expect ...I feel it is all about money, money....” (Participant 16)

The providers were paid per visit, they charged the patient per service. There was no long-term treatment plan budget. The parents ended up paying for a provider twice a week for years, they perceived themselves as a source of income to the healthcare professionals.

“Some professionals made a fortune from my son's case; my husband won't mind financing anything related to the treatment.” (Participant 23)

Some physicians wanted to get paid in advance and not to wait for the funding agency reimbursement. They also requested extra money in addition to the fees paid by the insurer.

“The physician took extra money before operating although the operation was covered by the National Social Security Funds”. (Participant 9)

Though these types of payments are informal and illegal, the parents were willing to pay to get the service needed.

2.1.5. Parent’s voice muted: becoming an unrecognized expert

Parents perceived themselves knowing their children the most and the best. They gained knowledge of the child’s capabilities, limitations, and preferences on daily basis; they were capable of looking at their child in a holistic manner while the professionals were only focusing on the disease. This expertise, developed by the parents, was not acknowledged by the professionals who rarely agreed to listen to them or take into account their point of views. They wanted the professionals to go beyond the clinical aspects to understand how they feel as parents (Gómez-Zúñiga et al., 2019).

Parents felt that their opinions were also unappreciated by the professionals. Sometimes as parents, they were aware of the delays of their children, but the physicians overlooked most of the time their opinion. One mother declared:

“We started to notice that there was something wrong. We started to compare his behavior to that of his eldest brother. I told the pediatrician that there was something wrong with the development of my son ... but he said that these delays were normal, some children experienced these delays in development ... till one day I went to the pediatric (firm tone) and told him that I want to conduct further diagnostic tests. I was struggling alone, I felt frustrated... I am the mother and I know. I want to investigate

more, I need answers. I am not insane, I am dealing with him every day and I know, I have another child I know how things should be". (Participant 2)

Another participant stated that when she revealed her worries to the pediatrician, he did not bother to consider her remarks.

"I told him that my son does not say a word while his brother (who is younger) is conscious and started to talk. He told me maybe because he is alone at home". (Participant 23).

Two mothers noticed their sons' developmental delays and shared their concerns with the professionals who completely ignored their observations.

"I started to consult several physicians, they all agreed that there were no signs of abnormalities. Physicians said that boys usually experience delays. I was not convinced, I started to read, to search the internet, and to attend conferences on developmental delays. I believed that there was something wrong, but the physician insisted that my son is fine". (Participant 10)

"I noticed at the age of two, but nobody believed me. I kept asking everybody, psychologist, physicians, neurologists until one neurologist agreed that yes there was a problem. If we had started earlier, it would have been much better.... It took two years, I kept going from one physician to another, then at the age of 4 years the symptoms became clearer and more obvious. The pediatric neurologist conducted an assessment for autism. Then, the pediatrician agreed that it was autism he said: "yes yes now I can notice autism, and the delays." Because the symptoms are now very clear, cannot be unnoticed." (Participant 19)

The physicians only took the parents' knowledge seriously after the symptoms became obvious. Consequently, this sometimes led to delays in starting the treatment. Some parents explicitly expressed their discontent that the providers disregarded their remarks.

"This was a waste of time for my son. Maybe I should have started the treatment previously but till I discovered I was already late" (Participant 17).

As one mother briefed.

"I had to tell him about his allergies and the complications related to intubation. My worries amplified since I believe that doctors do not take "non-doctor" notes seriously. However, I had no alternative; he needed this surgery under full anesthesia. I was worried. Later, his dentist recommended an orthodontist treatment. I tried to explain that he has a small respiratory canal unfortunately; the dentist did not consider my words he would have almost suffocated during the treatment. Sometimes, the doctors do not take into consideration the comments of the parents or let us say they do not give it proper attention. Maybe they think that if you are not a doctor you do not know what you are talking about." (Participant 1)

Parents require to be partners in their children's treatments plan and the healthcare provision. They want the providers to involve them in the care decisions. As one mother recalled a conversation with an ergotherapist:

"...she is my daughter, you (the therapist) will sit or stay with her quarter an hour, but I am living with her a whole life, and you need to take my opinion into consideration. You cannot take decisions by yourself!" (Participant 8)

This brings us back to reflect on the status of the patient or patient family in the healthcare system and to consider the emerging movement of expert patients. In this recent movement, the patient or his/ her family or representative as a member of the healthcare team. An “expert patient is a patient who has a significant knowledge of his/ her disease and treatment in addition to self-management skills”(Boulet, 2016). Expert patients can communicate effectively with healthcare providers, provide feedback on treatment plans, and get involved in decision making. They can even contribute in producing healthcare guidelines (Cordier, 2014). This calls for dedicated training in faculties of medicines on the importance of the contribution of the “expert patient” to the healthcare systems and to create program to educate patients (Friconneau et al., 2020).

2.2. Patient care path: becoming a care path manager

Caring for persons with disability requires the involvement of a wide range of health professionals over an extended period of time. Parents are the ones who have the greatest influence over the wellness of a child with disability since they accompany him or her from birth (Resch et al., 2010). Sometimes, they encounter difficulties when dealing with a fragmented healthcare system and this affects the quality of care and the wellness of their child (Resch et al., 2010). Our analysis revealed five main themes related to the challenges faced by parents of children with disabilities in the care path. These themes are: 1- the lack of support units, 2- the informational discontinuity, 3-geographical scattering of healthcare professionals, 4-the relational discontinuity and 5-the scarcity of certain assistive devices and services.

2.2.1. Lack of support units

The Lebanese health care system did not provide psychological support to the parents when they were informed about their child's disability. The parents were left alone at the announcement of the disability. Most of them clearly remember the details and describe this moment as disastrous.

A father summarized his feeling saying:

“It was the Day (c’ était le jour J de l’ enfer qui a déclenché tout) of hell that triggered everything” (Participant 21).

Another parent summed it all.

"Most of the parents when they get a child with disability, they feel that the world stopped."(Participant 26)

The parents felt lost when they were informed about the disability of their children. The healthcare professionals did not guide them through the care path. They felt helpless *"like a lost child"*.

"I felt like a lost child; I was 30 years old, but I did not know what to do." (Participant 23)

The support remained missing over the care path at the announcement of any new disease or condition even if it is a consequence of the main case. As one mother felt that she "died for the second time" when she knew about her daughter's heart disease though cardiologist problems are common in persons with down syndrome.

"Later, we knew about her heart disease as if I died for a second time. You die first when they announce the problem, and you feel that you die another time with each new complication. I screamed and said "she is trismic! Fine! We would learn how to live with her, but now we must wait and maybe she will live, maybe not. I died for the second time. I felt down and depressed. I felt I needed help; the parents should be cared for to be able to take care of their child. I did not know what to do or where to go. Nobody supports you before supporting the child, you need somebody to guide you." (Participant 16).

Later, when a new need emerged such as a treatment or a surgery, the system did not assist the parents or help them to find the providers. The parents were not guided through the system.

The parents referred to their family members, colleagues, or friends to identify the appropriate physicians or therapists and respond to their needs. One parent explained that when her child needed speech therapy, it was like a “*treasure seeking journey*”.

“We were asked to consult a speech therapist. It was the first time I heard that word. I did not know where to find one! Nor did any professional know of any speech therapist. Another treasure-seeking journey began. I started to ask friends who have schooled kids, persons working in the education field until I reached one.” (Participant 1)

Another mother shared the same “*trip*.”

“At the age of 3 months, the pediatrician who was following her said that there was a problem with her eye. At this moment, we started “the long trip of ophthalmologist”. First, whoever told us of a physician we consulted him. First, we searched for a pediatric ophthalmologist, we started with a physician, I don’t recall his name, then we went to one at Hospital R and whoever told us about a smart ophthalmologist, we used to consult him” (Participant 22).

Though several agents could finance the health care services and devices, the parents knew about them by chance. They were not informed about the financing agencies and their coverage schemes. A mother heard about the Ministry of Social Affairs financing role and support that could be provided at a shop.

“I was in a shop next to my house and my son was with me, the shop owner asked me if I benefit from the MOSA financing schemes her daughter has disability, and she is covered by MOSA”. (Participant 13)

2.2.2. Parents as the link between providers

Persons with disabilities might have multi-morbidities; they need multiple healthcare services that are usually performed by different health professionals. Persons with disabilities are usually transferred across boundaries of different care settings such as (primary and secondary). In highly fragmented healthcare systems, the professionals do not handle the transition through the care units. Their role is limited to their specialty and within their clinic.

Consequently, they work in parallel with the patient. without coordinating with the other providers. Sometimes, they even refuse to share information related to the patient's care.

“We started with the psychomotor therapy, later my son needed speech therapy...there is no multidisciplinary team, so we could not have all the treatments in one clinic ...and the challenge now is to make them talk to each other. Each therapist wants the other one to call with him or her: “Let her call me no let her call me!!!”and so on ...Once I asked for an evaluation and the pediatrician said that he will contact the speech therapist, but I don't remember if they had ever talk to each other ...and I was not aggressive enough to impose the coordination.” (Participant 10)

Most of the parents did not even receive a written medical summary of their children's conditions to help them handle the transition and transmit the required information to the next provider. One parent explained that the orthopedic requested physiotherapy sessions for her son, but the physician did not provide a report to guide the physiotherapist or to brief him on the child's condition.

“I have never got a report, or a letter addressed to the physiotherapist or on what to focus during the treatment session”. (Participant 3)

Another did not have a report on the condition, nor did the physician handle the presentation of the case to the therapist.

“So now, I had to present the case all over again! The therapist asked me about details of my son’s condition, but I was not knowledgeable; what I knew was that he had mobility difficulties”. (Participant 1)

Parents felt they were responsible for the coordination between the different providers which imposed “*lots of stress*” on the shoulders of the parents especially when they did not have a medical background.

“As a mom, I was tired. I had consulted too many doctors and explained the case repeatedly. It was incredibly stressful trying to explain a scientific case using my simple non-medical terms... I started to ask for copies of all medical tests results and for a discharge report each time my son had an operation. I built up his medical file”. (Participant 1)

Parents considered themselves as “*the link*” among the providers.

“I was the link between the physiotherapy and the doctor. The doctor wrote a physiotherapy demand addressed to the insurance company to get the coverage approval. I presented my son's case to the physiotherapist; I explained what was expected from these sessions”. (Participant 1)

Sometimes the parents were incapable or “*not convinced*” that they had to coordinate among the professionals. For example, a participant who knew that her daughter needed therapy decided to adapt a home-therapy program prepared by a group of therapists abroad.

“I was not convinced that I needed to go from one clinic to another and do the coordination. I applied to a home-based program, I implemented it at home and then I met with the professionals every six months, they assess my daughter progress and amend if needed.” (Participant 16).

As previously presented, the Lebanese healthcare system does not have a unified patient file. This created a challenge to the participants because they found themselves responsible for compiling the information related to their child’s conditions. Some parents asked the physicians to document the diagnosis and the treatment plan of their child in a summarized report. Some participants kept copies of the tests and X-rays. Those participants collected this data to facilitate the presentation of the condition of the child to a new care provider once needed. One mother complained that she is the only person who had the history of her son’s therapy plan.

“Nobody has a file of my son’s case only me!!!” (Participant 12)

A second participant stated:

“There is no complete file, each physician has part of my son’s medical file. I have my copy” (Participant 25)

2.2.3. Spending a life running from one clinic to another

Care provision in highly fragmented healthcare systems such as the Lebanese healthcare are usually spread out over various settings and impose an additional burden on families to be able to address their child needs.

The geographical scattering of the care clinics was a problem for the parents. They had to commute from one clinic to another. A parent clarified:

“There is no multidisciplinary team. Thus, he (her child) cannot have all the treatments in one place. (Participant 10)

Parents sought various therapies and sometimes at the expense of their own rest time, personal career, financial resources, and time spent with other children. The parents were exhausted *“physically and financially”*.

“My daughter had therapy sessions all week round. One therapy session per day, twice a week of each for a period of 2.5 years to 3 years. Every day, I picked her up from school to take her to the therapy sessions. I used to accompany her to a university center for speech therapy session, and another place for psychomotor therapy and she started to have sessions with a special educator to strengthen her capabilities. Later, I was tired, exhausted financially and physically.” (Participant 18)

“I lived 2 years in the car after that I felt drained and broke down, so I started to shift the training home, because my eldest son needed my presence as well” (Participant 28)

A mother said that a typical afternoon is spent in the car going from one clinic to another.

“We had to run between the school, the physiotherapist, and the speech therapist. We ended up exhausted with no time for rest: only schooling, therapies, and pain...All these issues made our life so difficult: lunch in the car, homework on the way back.”
(Participant 1)

One parent complained about “*spending a life running*” to catch up with therapy sessions.

“I used to run from one place to another to be able to attend a session, till now. We spent our life running, running.” (Participant 25)

Sometimes, one of the parents had to quit his or her job to be able to follow up her son’s treatment.

“I used to be a teacher, but I quit when I got my son because I had to go from one therapist to another, so it became difficult, and I could not make it all. I lived in the car literally. I spent all the afternoon going from one therapist to another. My second career was a “driver” and still till date. Really, I was going from the speech therapist clinic to the psychomotor clinic, then to the shewing therapist clinic. I lived 2 years in the car after that I felt drained and broke down, so I started to shift the training home, because my eldest son needed my presence as well” (Participant 28).

“My wife used to be a journalist, but she quit after my son was born because he needs a close follow up” (Participant 21).

2.2.4. Shopping for the right healthcare professionals

The healthcare professionals are liberal professionals working in private clinics and centers.

When a treatment was needed, the parents had to find professionals. They "shopped " for the "right healthcare professionals."

"The treatment was useless, the hip relocation failed and the "doctors' shopping journey" continued. Literally, we were running from one orthopedic to another, from one hospital to another with no answers. His case was presented to around ten doctors in less than three months. All of them were not experienced with his condition...till we found the right orthopedic that was really caring and humanistic" (Participant 1).

Sometimes the parents started the treatment but then they changed the therapists many times when there was lack of commitment from the providers or when the child's situation did not improve. For example, one mother revealed that she worked with more than ten speech therapists till she found a "good therapist".

"I started to look for a speech therapist. I cannot tell you how many therapists I visited. The first therapist did the assessment but excused herself because that she does not have time for him, so why did you do the assessment? The second one was committed for the first two months twice per week. Then every now and then there was an excuse. I had changed more than 7 or 10 therapists over a short period of time. This is a waste of time for my son.... We changed many speech therapists till we met her, she was good, helpful, and my son liked her." (Participant 17)

2.2.5. Scarcity of certain assistive devices and services

Sometimes the parents did their own research to find ways to help their children with disabilities. The parents searched to find apparatuses that could help the development of their

children. For example, a child was unable to talk nor to move his body. His father searched the internet for a communication device for his child, and he discovered the eye tracker. He bought one from abroad so that his son could type using his eyes movement. The mother explained.

“My husband is a computer engineer, so he researched all the time about how technology could help us. We need to create a means of communication with our son. He found a tool called the board; the person could use his eyes to choose the letters. We bought the first one when it was invented and then we bought another one after being developed. It is nothing, a sticker, the size of a lentil, put between the eyes and you look at the screen and you choose the letter, this was the first one, now there is no sticker you just look. The first one was 4000USD, the second is 1500USD, someone got it from USA. It is like a small pen you put it over the screen”. (Participant 12)

Sometimes the parents’ personal research led them to discover therapies applied abroad but not available in the country. They used their network to find such treatments.

“I did my own research and read about my son’s condition, and I found that the Applied Behavior Analysis (ABA) therapy is the only evidence-based therapy, which was studied, and it had a particularly good outcome. I started to search for ABA providers in Lebanon. I could not find anyone but instead I found a family that has done ABA therapy to their daughter. I met the motherand she introduced me to an ABA therapist”. (Participant 19)

Another parent explained that a neurologist informed her about ABA therapy, and he told her that it is not available in the country. She contacted other mothers who have autistic children and financed the training of ABA therapists.

“The neurologist told me that if you can afford to go to the travel go. Your son needs an Applied Behavioral Analysis treatment, and it is not available here. Applied Behavioral Analysis is the only scientifically proven method that improves the situation of kids with developmental or behavioral delays”. (Participant 10)

The results presented in the above sections revealed two emergent roles of the parents to overcome the failures of the highly fragmented healthcare system. The first role is the patient expert presented in the previous section. The second role is the parent as care path manager. A case or care path manager role is an expert clinician whose role is to choose the most appropriate treatment, to coordinate the care of patients and to ensure the optimal use of the available resources (Fabbri et al., 2017).

Table 8: The roles played by the parents and their responsibilities

Parents' Role	Responsibilities
Patient Expert	<ul style="list-style-type: none"> - Has Knowledge about condition and treatment condition - Has Self-management skills
Case / Care path manager	<ul style="list-style-type: none"> - Chooses the treatment - Coordinates between providers - Negotiates with the financers

Source: Prepared by the author

As patient experts, the participants became full members of the healthcare team. As a care path manager, the parents' role consisted in choosing the providers and the treatment plans, coordinating between healthcare professionals, and ensuring the financing of the services.

These roles of the parents emerged as a response to the gaps identified in the highly fragmented healthcare system. This leads us to examine more in-depth the structure of the system coverage.

2.3. Fragmented complex system coverage structure

The analysis of the interviews reveals two main challenges related to the structure of the healthcare system: the bureaucracy burden of the approval processes and the financial burden of service provision. The latter challenge showed two main sub-themes, mainly the ceiling of the coverage schemes, and the exclusion of certain therapies and assistive devices.

2.3.1. Bureaucracy Burden

Bureaucracy burden has been mentioned by parents as a major issue in the coverage of care of the services provided to their child.

Parents need to get pre-approval for the purchases of certain services and devices to benefit from a partial reimbursement. The pre-approval process was described as a challenging experience.

Parents “*suffered*” from the bureaucracy of the approval processes and procedures.

“You suffer a lot, lot of bureaucracy... You suffer a lot to get an approval.” (Participant 9)

“Don’t remind me of the suffering with the funding agency. The agency covered only 10 sessions per month and 15000 per session and the suffering, and bureaucracy ...don’t remind me of those days....it has to be renewed monthly”. (Participant 26).

A participant explained that she has social security (NSSF) coverage, but she “*fought to get a refund.*”

“I claimed the cost of the hearing device from the insurer. They (the employees) asked to see the child, so I took him to their offices. We waited half a day, and my child was crying most of the time, and the result was that they covered 80% of the most basic hearing aid as per the insurer estimated price. Which is nothing!!!” (Participant 15)

Some participants explained that they stopped claiming reimbursement or coverage from the public funds due to their complex bureaucracy procedures. As one parent explained:

“Although I had public coverage, I have never used it. It is a long and tiring process. I tried to use it once to cover a surgery, but I had to wait for long time, so I gave up and never used it again”. (Participant 5).

Sometimes, the representatives of the financing agencies requested to see the patient in person. This created anger and stress, the patient who is sick had to bear the burden of transportation and attendance at the offices of the financier. This sometimes was exposed to more medical risks.

For example, a mother explained in an angry tone:

“The insurer refused to cover the test and the employee asked us to bring our son to their offices. At that time, his immunity was extremely low, his travels were limited between home and the hospital. We were registered in at an office located in the suburban of Beirut, more than ½ an hour from home lived. We brought our child there; when the employee saw how sick he was; he proclaimed that we were not supposed to bring him here I told him you didn’t believe us that he is sick, and he needs these tests!!!” (Participant 4)

2.3.2. Financial Burden

Parents are faced with economic constraints that are not limited to the health services provided. Caring for a child with disability demands financing multiple care services and maybe some assistive devices over a long period of time. As one mother (Participant 10) said *“kids with disabilities need money”*. A parent declared that sometimes the scarcity of the *“financial means may stop you from reaching your goal”*. (Participant 22)

To better understand the financial challenge experienced by the parents of children with disabilities, we tried to identify its main causes. We noticed two main sub-themes: 1-the rigid ceiling for coverage and 2-the exclusion of services and assistive devices from the coverage schemes.

2.3.2.1.Ceiling of the coverage schemes

The coverage schemes, whether public or private limits the maximum number of treatment sessions per patient per year. The parents had to cover these therapies out of their pockets.

“I had problem in financing the physiotherapy sessions because the MOPH covers only two sessions of physiotherapy.” (Participant 9)

“The NSSF covered only 20 sessions of physiotherapy, then I started to pay out-of-pocket till I reached a phase when I was unable to pay for it at that hospital” (Participant 4).

The insurers imposed two types of ceiling: one related to the frequency and number of sessions over a period of time and another linked to the monetary amount covered per year or per disease.

Participants explained that the coverage plans had a maximum number of sessions per period. The ceiling is fixed regardless of the case needs:

“The physician recommended physiotherapy treatment. The NSSF would reimburse 12,000 LL of 35,000LL after 4 months for only few sessions per month while her case needs a session every day”. (Participant 24)

“We applied to get an approval to cover at least the physiotherapy sessions. The NSSF covered only 10 sessions per month ...the suffering, and the bureaucracy ...do not remind me of those days...and the approval had to be renewed monthly.” (Participant 26)

Another example is that of a group insurance scheme that defined a maximum limit on congenital diseases coverage as one mother explained.

“The first two surgeries were covered by group insurance. The insurance refused to cover the third surgery because the coverer considered that we exceeded the limits of coverage for congenital diseases”. (Participant 11)

“The family benefitted from the Order of Engineer group insurance to cover the in-patient treatments, laboratory, radiology, and physiotherapy services provided at a determined list of centers. The ceiling for congenital disease was 5,000,000 Lebanese Pounds i.e., 3,333\$ per year. The amount exceeding the ceiling were out-of-pocket”. (Participant 1)

And also, a public scheme setting a maximum fee per device and service.

“The COOP reimbursed a minimal amount, the test cost 300\$, they reimbursed 50,000 LL around 33 \$” (Participant 22)

All schemes impose co-payment ratios for covered services and devices. The ratios vary among insurers and according to the service type. These co-payments created challenges for the patient.

Other participants described their experiences.

“A test costed 300\$, the COOP reimbursed 33\$ A small sum of the consultations fees was reimbursed for example the fee is around 100 USD, the COOP will reimburse 24,000 LL i.e., 16\$. But we did not care about the financial burden, we needed hope only”. (Participant 22)

“She also has dental problems; she needs an operation. The NSSF will partially cover the surgery, but the co-payment is around 3000\$, I cannot afford it right now. So, we postponed it.” (Participant 18).

2.3.2.2.Exclusion of services and devices

In addition to the ceiling imposed by coverage schemes, some therapies such as speech and motor therapies were also excluded.

“We have a 100% coverage insurance, but they refused to cover my son’s treatment because he has a congenital disease”. (Participant 27)

“...My problem was not with the hospital admission fees; it was with the cost of the socio- medical sessions”. (Participant 6)

The plans also exclude some tests and assistive devices. For example, the Cooperative of Civil Servants Fund does not cover an eye test nor a magnifier.

“The electro diagram was not covered, and the magnifier also is excluded. This year my daughter needed a new magnifier, and its cost was a “challenge. I was worried and kept up waking up and crying at night; the absence of the magnifier could stop her future. You know the salaries are fixed and we are paying the schooling, the shadow teacher and all of these commitments and then unpredictably faced by the payment of 1600\$ for sure.” (Participant 22)

The schemes could exclude some surgical accessories as one participant revealed.

“My daughter needed two hip surgeries. It was a tough experience.... but we paid for the protheses. We paid 1000 USD!” (Participant 26)

Sometimes parents had to stop the treatment sessions because they could not afford the financing cost as some participants revealed.

“My daughter has been having psychology sessions for 3 years, now I cannot afford the psychologist sessions fees, so we stopped the treatment” (Participant 18)

“We could not afford the treatment sessions anymore” (Participant 25)

The out-of-pockets payments are a huge challenge for some families. As one mother explained:

“I was financially drained, with the economic situation, I could not afford anymore.” (Participant 28)

In Lebanon, the socio-medical services are paid out-of-pocket, and they are not reimbursed by the financing agents. As out-of-pocket is a major burden on families, we tried to estimate the out-of-pocket costs incurred by the parents from the birth of the child and till the date of the interview. This was a difficult exercise as families had to recall details that might have been completely forgotten. We, therefore, tried to help them remember the frequency and the cost per session. The two main costs recalled by the participants were the cost of socio-medical services and the cost of schooling. In fact, participants do not recall how many times they paid for physicians' consultations, consequently, we have limited the costs of medical services to the major interventions.

Table 9: Estimated out-of-pocket care payment: the case of a family having a child with Autism

Case	Disability	Diagnosis	Date of birth	Cost till the day of the interview in USD	Cost per year per USD
10	Autism	Early childhood	2006	540,193	8,585
19	Autism	Early Childhood	2002	254,213	14,123
23	Autism	Early Childhood	2003	533,173	31,363
28	Autism	Early Childhood	2003	330,320	19,431

Source: Prepared by the author

In addition, the medical fees are usually covered or reimbursed by the private and public agencies. According to the above table, caring for an autistic child would cost between 14,123 USD and 38,585 USD a year.

Given the burden of the treatment, some parents had to give up all their personal plans to be able to finance the treatment of their children. As one participant testified:

“We are middle class family; we have no inheritance. We were fighting for this girl, we decided not to have another child, not to buy a house to be able to finance her needs.”
(Participant 18)

Summary of chapter 2

In this chapter, we presented the challenges faced by parents of children with disabilities resulting from the fragmentation of the Lebanese healthcare system. These challenges identified were mainly at three levels: 1-the interaction between the parent and the provider, 2-the care path, and 3-the structure of the Lebanese healthcare system. These challenges associated with the perceived failure of the healthcare system and its inability to provide the parents with the required support and answers to their needs resulted in two emerging key roles for the parents: the expert patient role and the case manager role.

Our analysis revealed that the main burden results from the fragmented and complex structure of the healthcare system. Twenty-eight out of the twenty-nine participants mention ninety-four times the financial burden as a major challenge. The Lebanese healthcare system excludes the coverage of some healthcare services increasing the out-of-pocket payment of the households and leading sometimes to catastrophic expenditure.

The healthcare system structure does not provide support to the patient and / or his family. This lack of support is the second main burden identified by the participants. The Lebanese healthcare system does not provide a gatekeeper or case manager at the entry point which results in forcing the parent to play the role of patient expert and case manager.

The third major problem results from the interaction between the patient and the provider. The parents are not provided with enough information about the case of their children. They do not know the real consequences of the disability of their child. They feel like they need to “beg” the physician to tell them what to expect, and what to do. Some parents explained that when the physicians provide them with reports regarding the case of their children, it is written using medical jargon, which is very difficult for them to understand. Table 10 below presents in descending order the recurrence of codes revealed from the empirical data analysis. These codes present challenges described or mentioned explicitly by the interviewees.

Table 10: The challenges according to their density in descending order

Category	Code	Frequency of codes	Recurrence of codes
System coverage structure	Financial Burden: ceiling of coverage schemes and exclusion of services and devices	28	94
Patient Care Path	Need for support units	15	34
Parent- Provider Interaction	Incomplete information and medical jargon	14	33
Patient Care Path	Informational Discontinuity	11	27
Parent- Provider Interaction	Parents ‘voice muted	10	20
Patient Care Path	Geographical scattering of service providers	10	21
Parent- Provider Interaction	Concealing the bad news	11	19
Patient Care Path	Relational Discontinuity	11	19
Parent- Provider Interaction	Parents as a goose with golden eggs	9	15
Patient Care Path	Scarcity of certain assistive devices or services	6	11
Parent- Provider Interaction	Not false hope but encouragement	7	9
System coverage structure	Bureaucracy Burden	6	6

Source: Prepared by the author

As shown in the table above, the exclusion and coverage ceilings are the main challenges while the bureaucracy burden appears as the least challenging. Exclusions and coverage ceilings are

the major malfunctioning of the system, it is mentioned by 28 participants 94 times. Followed by the parents' need for support units, which was explicitly mentioned by 15 participants 34 times, then the incomplete information provided to the parents and the medical jargon used by the professional. Then, the informational discontinuity explicitly mentioned 27 times, while some parents supposed that there is no need for the professionals to coordinate with each other because everyone has a different job to do.

Being in an abductive approach, we confronted our empirical findings against scientific literature. This allowed us to identify emergent themes related to inequity of care and to compassion organizing frameworks. We will therefore analyze in the following chapter the perceived failure of the healthcare system through the lenses of these two frameworks.

Chapter 3- Analysis of the failures of a fragmented healthcare system

We have presented in the previous chapter the challenges faced by parents of children with disabilities in the provision of healthcare that stemmed from the highly fragmented Lebanese healthcare system. We have also identified the emergent roles taken by the parents to overcome the gaps in the system. This led us to propose an analysis from two new theoretical perspectives.

This chapter is divided into two sections. Section one presents the challenges of the fragmented healthcare system in light of Levesque et al. (2013) inequity of access to care framework. Section two analyzes the causes of these failures through Dutton's et al. (2006) compassion organizing framework.

3.1 Inequity of access to care

Health is a basic human right according to the International human rights agreements (*Treaties and International Agreements Registered or Filed and Recorded with the Secretariat of the United Nations*, 2008). Health is a physical and mental status, it means wellbeing. Health equity is the “absence of systematic disparities in health and the determinants of health” including social determinants (Griffith et al., 2017). Hence, health inequities “are systematic differences in the opportunities groups have to achieve optimal health these disparities lead to unjust and avoidable differences in health outcomes” (National Academies of Sciences et al., 2017).

This subsection is divided into two sections. Section 3.1.1. presents Levesque et al. (2013) framework on and section 3.1.2. analyses our results based on Levesque et al. (2013) framework.

3.1.1. Inequity of care framework.

“Inequity (of care) is the presence of systematic and potentially remediable differences among population groups defined socially, economically, or geographically”.(Starfield, 2011)

Our health is a matter of daily concern, we need to be healthy to be able to go to school, to work and to participate in the community. Thus, health equity is a public health priority (Peterson et al., 2021) especially for countries adopting the universal healthcare coverage (Cu et al., 2021). A universal health coverage system aims to ensure that all people have access to needed health services without being exposed to financial hardship (WHO, 2022).

Box 2 : WHO definition of Universal health coverage

Universal health coverage means that all people have access to the health services they need, when and where they need them, without financial hardship. It includes the full range of essential health services, from health promotion to prevention, treatment, rehabilitation, and palliative care.

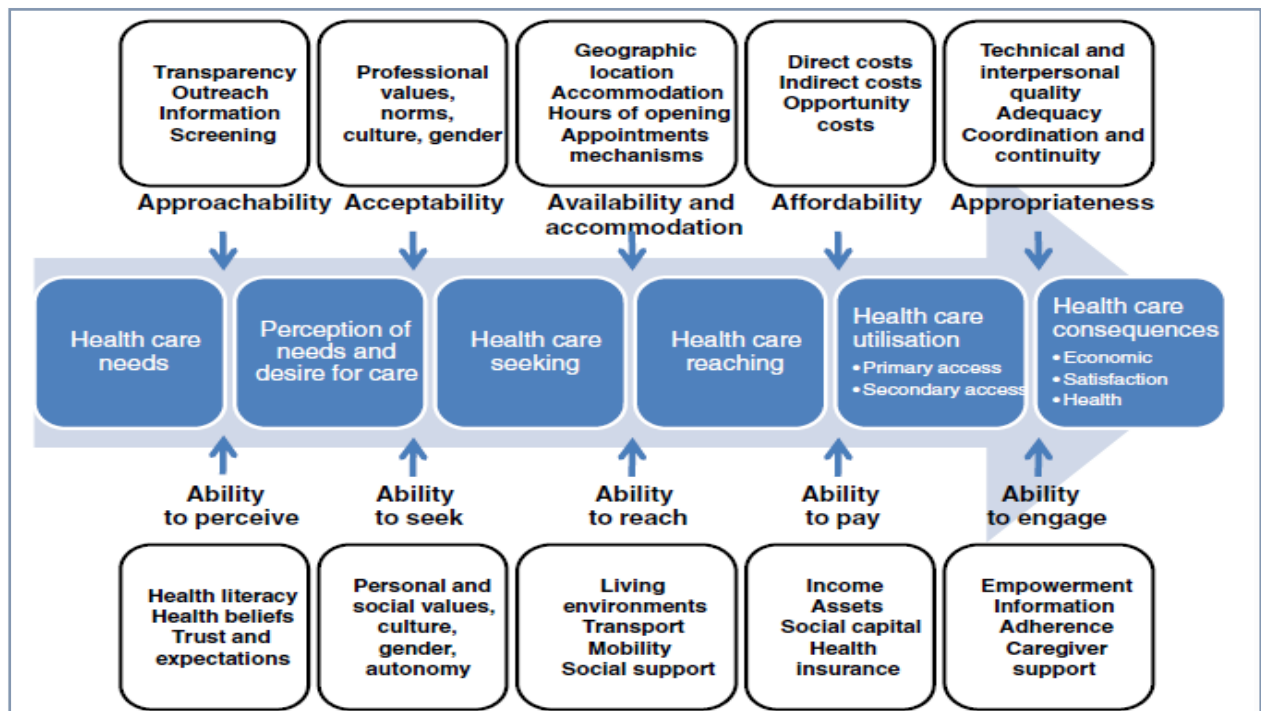
To make health for all a reality, we need: individuals and communities who have access to high quality health services so that they take care of their own health and the health of their families; skilled health workers providing quality, people-centered care; and policymakers committed to investing in universal health coverage.

Universal health coverage should be based on strong, people-centered primary health care. Good health systems are rooted in the communities they serve. They focus not only on preventing and treating disease and illness, but also on helping to improve well-being and quality of life.

Source : (WHO, 2022)

Access to care is a complex concept, it includes various dimensions such as the financial, the geographical, the regulatory and others (Levesque et al., 2013, p. 3). Despite the multiplicity of access to care frameworks, Levesque et al. (2013) operational framework is being successfully used in researches on inequity of access to care (Cu et al., 2021). The performance of the healthcare system is entangled with the access to care in its wide sense.

Figure 9: Levesque et al. (2013) conceptual framework of access to health care



Source : (Levesque et al., 2013)

Levesque et al. (2013) framework is the result of a comprehensive review of the literature on access to care. It presents a multidimensional view of access to care in the context of healthcare system taking into account the patient and the health system perspective (Cu et al., 2021). This framework identifies five dimensions of accessibility of the system (on the upper side) and five corresponding abilities of patient or population (on the lower side). This framework allows us to understand whether the barrier to access is related to the patient abilities (to perceive, to seek, to reach, to pay and to engage) or to the system dimensions. The abilities and dimensions interact together and influence each other during a period of treatment. For example, the location of clinics imposes high cost of commuting and thus affects the ability to pay for a service.

3.1.2. The inequity of the Lebanese healthcare system in light of Levesque et al. (2013)

To assess the equity of access of the Lebanese healthcare system, we present our results according to Levesque et al. (2013) healthcare dimensions : approachability, acceptability, availability, affordability, and appropriateness.

Approachability

Approachability, as defined by Levesque et al., “relates to the fact that people facing health needs can actually identify that some form of services exists, can be reached, and have an impact on the health of the individual.” Its corresponding ability is the ability to perceive that such a service exists. (Levesque et al., 2013, p. 5).

Participants described the Lebanese healthcare system as a complex and opaque system, a “maze”. They mention that many efforts are needed to navigate in such a system where multiple providers, financing agents and service delivery organizations exist. They also pointed out the difficulty of identifying, in such a system, the available services, as well as the relevant and helpful information that could ease their journey. The two quotes below provide examples of such services, speech therapy and information, disability card, that would have been helpful.

“After that my son needed speech therapy. It was the first time that I heard that word. I did not know where to find one!... Another treasure-seeking journey began”.
(Participant 1)

One of the participants identified that she knew about the disability card provided by MOSA and its benefits by chance.

“I was in a shop next to my house ... the shop owner asked me if I benefit from the disability card allowances...She said that her daughter is at a special school covered by MOSA”. (Participant 13)

The absence of visibility of the services renders it non-approachable to the users and the lack of knowledge of the available services thus creates a barrier to care access. Both these issues, contribute to increasing inequity in care.

Acceptability

“Acceptability relates to cultural and social factors determining the possibility for people to accept the aspects of the service (e.g., the sex or social group of providers, the beliefs associated to systems of medicine) and the judged appropriateness for the persons to seek care. Its corresponding ability is the ability to seek health care.”(Levesque et al., 2013, p. 5)

The parents' experience with the healthcare providers did not show acceptability as a barrier. However, some participants mentioned unencouraging interactions with members in the society. As one mother stated:

“Once, we were at the clinic. My daughter started to play with another kid waiting for her appointment... her mother called her kid and asked her to stop playing with my daughter” (Participant 22).

In healthcare facilities, individuals do not only interact with healthcare providers, they also interact with other patients. The behavior of the latter may jeopardize the ability of a parent to seek help, especially if it is judgmental or discriminative.

Availability and accommodation

Availability and accommodation refer to the fact that health services (either the physical space or those working in health care roles) can be reached both physically and in a timely manner. Its corresponding ability is the ability to reach.” (Levesque et al., 2013, p. 5)

The geographical scattering of providers also creates a barrier to access to care since not all parents have the necessary resources to commute between clinics. Some participants had to quit their jobs to be able to care for their children resulting in an increased financial burden. Families were obliged to live on a single income and support all expenditures related to the treatments among which the transportation cost among clinics.

Availability and accommodation also include accessibility of premises. Parents complained that some clinics are not adapted to accommodate persons with disabilities:

“Her clinic was at the 8th floor, sometimes there is no electricity, so we need to climb the stairs till the 8th floor”. (Participant 10)

Affordability

“Affordability reflects the economic capacity for people to spend resources and time to use appropriate services. It is corresponding ability is the ability to pay” (Levesque et al., 2013, p. 5).

The crucial challenge identified by the parents relates to the financial cost of the services and devices needed. Some participants were “forced to stop” some therapies because they were

unable to pay the fees; while others expressed “*thankfulness to God*” (participant 3) for being able to finance their children’s treatments. These services fees are mostly paid out-of-pocket as most public and private coverage schemes in the Lebanese healthcare system do not cover them. A mother, who has two insurance policies, the National Social Security Fund and a private insurance, explained that:

“The covering agencies do not cover therapies starting with a “psy” such as psychology, psychomotor therapies.” (Participant 2)

The parents felt frustrated and helpless because the financial burden is amplified by the ceiling of the coverage schemes. Children with disabilities need multiple interventions over long periods of time; as such, they require several services that can easily and rapidly extend beyond the approved ceiling.

“The experience of 2011 was different and tough. It was the first time I experienced how weak, frustrated, and desperate a person can be when his son needs an obligatory medical treatment, and he cannot afford it”. (Participant 1)

The Lebanese healthcare system privileges fee-per-service payment modalities. This incentivizes the physicians to provide excessive care (Elhauge, 2010). Moreover, informal payments aggravate the financial burden faced by families. Some studies point out that in case the patient cannot afford the informal payment he might not be able to get the service (Mossialos et al., 2005). “In a fragmented system it is common to ignore the poor, the manufacturers produce the products based on economic niche more than public good (Stange, 2009)”.

Appropriateness

“Appropriateness denotes the fit between services and clients need, its timeliness, the amount of care spent in assessing health problems and determining the correct treatment and the technical and interpersonal quality of the services provided. It is corresponding ability is the ability to engage” (Levesque et al., 2013, p. 5).

The empirical data highlighted that the participants perceive the healthcare system as not inclusive and not adapted to the complex need of their children. Some professionals were rigid and resisted amending or adapting a service or procedure to meet the needs of the child with disability. The changes proposed by the parents to a procedure or service were minor changes; they aimed to fit the limitations of their children and to decrease any potential anxiety. Such changes would have provided the suitable environment required to ensure better outcomes.

As a mother shared her experience:

*“Everybody wants my son to adapt to his or her way of doing things not the other way round. Once he had an accident at school and broke his teeth. The physician decided that the treatment would be performed at the dentist clinic otherwise the insurance would not cover the fees... I tried to explain that it is impossible to do this procedure at the clinic because my son would not allow the dentist to fix his teeth. This procedure should take place at the hospital and my son would need full anesthesia... The physician was not convinced. I told him: ” great, if you could let him sit down, I have no problem”. Eventually he could not, and he approved to perform the procedure at the hospital. If he were convinced from the beginning, we could have saved three hours”.
(Participant 2)*

Table 11 below presents the most expressive verbatim per each healthcare system dimension according to Levesque et al. (2013) framework.

Table 11: Most expressive verbatim per dimension

Dimension	Corresponding ability	Results
Approachability	The ability to perceive that such a healthcare service exists.	After that my son needed speech therapy. It was the first time that I heard that word. I did not know where to find one!... Another treasure-seeking journey began". (Participant 1)
Acceptability	The ability to seek health care	"Once, we were at the clinic. My daughter started to play with another kid waiting for her appointment... her mother called her kid and asked her to stop playing with my daughter" (Participant 22).
Availability	The ability to reach	"Her clinic was at the 8th floor, sometimes there is no electricity, so we need to climb the stairs till the 8th floor". (Participant 10)
Affordability	The ability to pay	"The experience of 2011 was different and tough. It was the first time, I experienced how weak, frustrated, and desperate a person can be when his son needs an obligatory medical treatment, and he cannot afford it". (Participant 1)
Appropriateness	The ability to engage	"Everybody wants my son to adapt to his or her way of doing things not the other way round

Source: Prepared by the author

The analysis of the Lebanese healthcare system revealed several challenges to access resulting mainly from the fragmentation of the system; these have been identified at different dimensions. Their interaction created a cumulative effect which amplified the inequity of access to care.

3.2 The roots of the lack of compassion organizing

“Care and compassion, it would seem, may emerge where they are least expected and may well be endangered where they are most expected”. (Rynes et al., 2012, p. 503)

Compassion is rooted in all human beings, it is an innate human instinct to response to other's suffering (Dutton et al., 2006). It is as an “empathetic reaction to another's suffering” (Madden et al., 2012). Suffering is the “experience of pain or loss that evokes a form of anguish that threatens an individual's sense of meaning about his personal existence” (Dutton et al., 2006).

Compassion as a reaction to alleviate someone's suffering involves noticing the pain of others, feeling empathy and responding with an aim to ease the suffering (Lilius et al., 2011). Compassion reveals itself as care, trust, friendship, or partnership. It is expressed through minor acts such as holding a hand, speaking comfortingly, listening to a complain, explaining an action or a decision, and encouraging someone to feel better (Frost, 1999; Sinclair et al., 2016).

Although compassion is considered fundamental to healthcare systems, this belief has been challenged by patients experiencing lack of compassion (Papadopoulos & Ali, 2016; Sinclair et al., 2016; Straughair, 2019). Some researchers explain this lack of compassion at the individual level of the healthcare providers by “compassion fatigue” from being exposed to high level of negative emotions and distress of others (Kahn, 2019, 2019; Simpson et al., 2020), others explain the lack of compassion could be due that the providers are busy and preoccupied or maybe the providers notice the pain but they withheld the response. (Madden et al., 2012). This section focuses on the inability of the system to organize compassion. It aims to understand the capability for compassion at organizational level and not the individual level

because we assume that the healthcare professionals decide to enter the profession with virtuous intentions to help and serve humanity with compassion (Simpson et al., 2020).

Our results revealed a non-compassionate healthcare system. We argue that underlying the uncompassionate healthcare system is an amalgam of contextual features that constrain organizing compassion. We consider the Lebanese healthcare system as a network, with the main stakeholders of which are the providers, the regulators and the patient or his / her representative. The patient or his / her representative is not considered an integral part of the healthcare organizations (hospital, clinic) nevertheless, he / she is an important stakeholder of the healthcare system as a whole.

In the following part, we present the compassion organization theories that we used as a reading lens during our analysis process. Then, we will analyze the elements of the Lebanese healthcare system and their effects on compassion organizing. We end this section by discussing our results.

3.2.1. Literature review on compassion organizing

Compassion involves a response to release the suffering of others. While compassion organizing is *“a collective response to a particular incident of human suffering that entails the coordination of individual compassion in a particular organizational context”* (Dutton et al., 2006).

Thus, compassion is the feeling that arises when a person witnesses the pain of another and act to alleviate the suffering while compassion organizing is when the members of an organization witness this pain and respond to the human pain in a coordinated manner (Dutton et al., 2006).

Therefore, compassion involves making decisions and behaving in ways that reflect concern and care (George, 2013). Compassion organizing is a collective response that requires the coordination of individual compassion in an organizational context through adapting the organization's normal routines and structures (Shepherd & Williams, 2014).

Various studies have been conducted on how the organizations respond to the suffering of its members (Dutton et al., 2006, 2014; Kahn, 2019; Lilius et al., 2011; Madden et al., 2012; Watkins et al., 2015). Through an abductive approach, we relied on three main frameworks to analyze our data. The first framework is compassion organizing theory of Dutton et al. (2006), the second is Lilius et al. (2011) framework theory on compassion capability and the third Madden et al. (2012) framework on the emergent organizational capacity for compassion, These frameworks are presented in the following subsections.

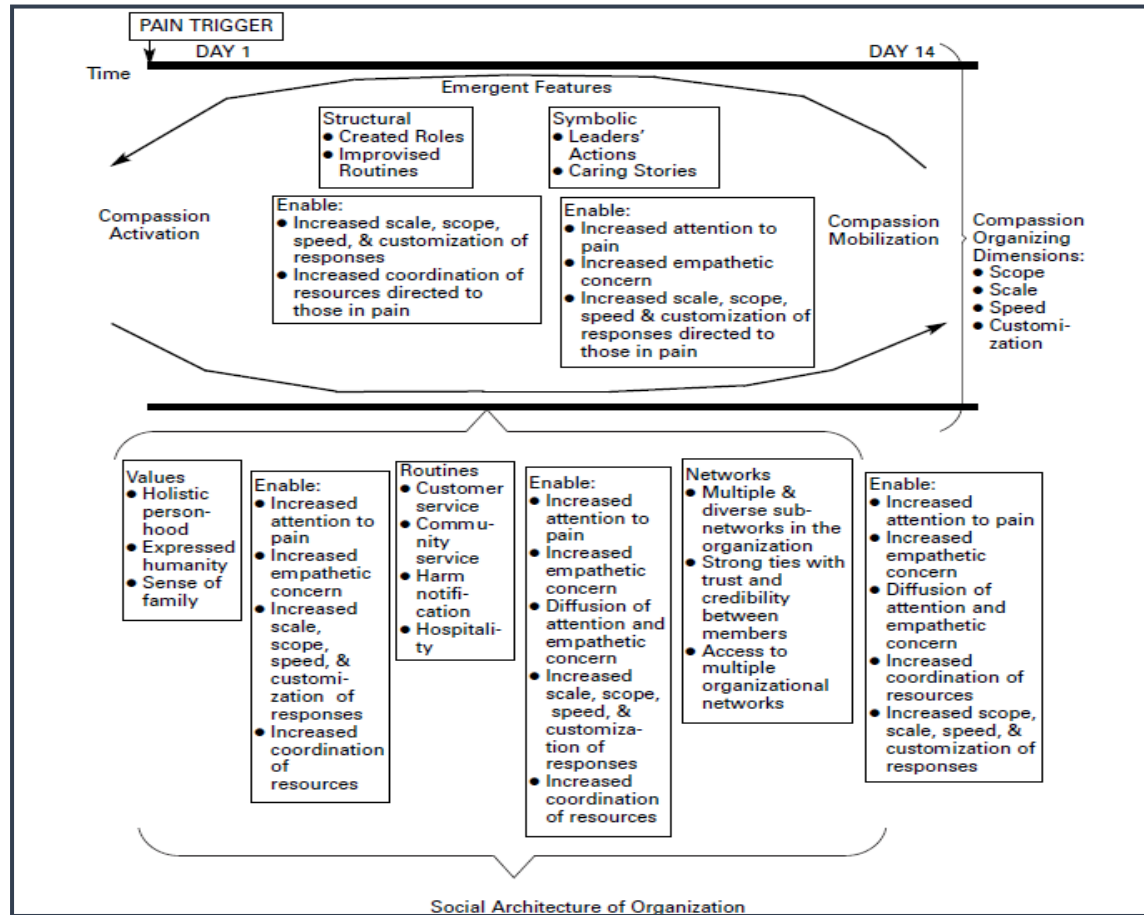
3.2.1.1. Compassion organizing theory

Dutton et al. (2006) theory showed that compassion as a collective act depends upon a social architecture of the organization.

Dutton et al. (2006) theorized that the ability of the individual to notice the pain and the contextual features can turn an individual compassion into a social reality that commands collective attention. Dutton's et al. (2006) compassion organizing theory relies on human agency and the social architecture of the organization. The notion of compassion is irrelevant if the individual is not capable of noticing another person's pain. Therefore, the theory presumes that the individual is capable of noticing, feeling, and responding with the intention to ease the other person's suffering. Dutton's et al. (2006) theory on compassion organizing explains how a noticeable pain activates the attention of others, the feeling of empathy, and an

action to acquire and coordinate resources from an organization with an aim to alleviate the anguish.

Figure 10: The process of compassion organizing



Source : (Dutton et al., 2006)

Dutton et al. (2006) suggest that compassion organizing has two consecutive stages: compassion activation and compassion mobilization. Compassion activation is noticing and feeling another's distress. Compassion mobilization refers to acquiring and coordinating resources from an organization. Compassion activation is a cognitive capacity while compassion mobilization is a behavioral response that entails the availability of resources. Compassion activation and mobilization are enabled by the social structure of the organization.

The fragmented healthcare structure might enable or restrict people from calling collective attention to pain, spreading feelings of empathy i.e., activating compassion. Whether compassion activation might lead to compassion organization depends also on this structure. Thus, the interaction of the human agentic response and the elements of the organization social architecture define whether compassion activation leads or not to compassion mobilization. It is through the organization's social architecture that people are able (or not) to call collective attention to pain and spread feelings of empathetic concern that are likely to prompt a response. The elements of this social structure are shared values, routines, and networks.

According to O'Reilly and Chatman as quoted by Dutton et al. (2006), shared values "define what is important in an organization and create expectations about how to act in different situations". Swidler (1986), quoted by Dutton et al. (2006), argues that shared values "lead to strategies of action" making meaning of the actions. Values are defined as embedded assumptions, expectations, and emotions (Dutton et al., 2005). Assumptions define what is considered as "good or bad", expectations are the expected acts in different situations and emotions are associated with what is worthy. Dutton et al. (2006) identified three shared values that fuel the incentives to act and help others. These values are holistic personhood, expressed humanity, and sense of family. These shared values affect the activation as well as mobilization of compassion. Holistic personhood value means that the person is not limited to his or her formal role, this shared value incentivizes the members of the organization to treat the person holistically. Accordingly, the person is not only an employee in an organization, but he or she might also be a victim of a fire, or a member of a family suffering from the chronic illness of one of its members. Considering a person holistically enables the expression of humanity and

incentives the sense of family. Their interactions allow the members of the organizations to notice the pain and respond collectively to alleviate it.

Routines are sustained interaction inside an organization. They are patterns of actions that requires little thought (Dutton et al., 2006). These routines construct the capabilities of the organization, and they are critical to compassion organizing. Routines could be considered as a form of resource that enabled people to notice, feel, and respond to the students' pain (Dutton et al., 2006). In Dutton's et al. (2006) the student services routines allowed noticing and responding to the pain of the victims of the fire in quick and legitimate manner. The university civic engagement routines helped spread attention toward the pain, provide legitimacy to noticing the pain and facilitated the coordination of people's responses. The routines of notifying the members of the university through email facilitated the activation of compassion towards the students affected by the dormitory fire. The routines of hospitality allowed providing housing to the students who lost their rooms; thus, it facilitated the mobilization of compassion.

Network is the structure of interpersonal connections between members of an organization and between members of different organizations (Dutton et al., 2005). It is the third feature of the organization social architecture. The availability of a multiple and diversified network characterized with strong ties, trust, and credibility, and that has access to multiple organizational networks enables compassion organizing (Dutton et al., 2006). The network facilitates spreading knowledge about the pain trigger which is compassion activation. Network expands the spread of information about suffering; thus, the pain trigger reaches many people and generates awareness among them. Network allow the spread of emotion such as empathetic

concern (Dutton et al., 2006). Thus, compassion activation might be enhanced. In the case Dutton et al. (2006), when Kellie notified the women faculty group and the student services group of the fire at the dormitories, the message was spread to large number of people, and this facilitated compassion activation. The network helps in providing knowledge about the resources needed to those responding to the pain trigger, which is compassion mobilization. In the case of Dutton et al. (2006) the members of the group started a quick extraction and coordination of resources.

Dutton et al.'s (2006) article identifies emergence of two types of features. The structural features which are improvised roles and the symbolic features, such as leadership actions and stories.

The created roles are informal and unofficial roles that emerge during the process, as Karl in Dutton's and al. (2016) case. Karl, a student in the university, turned out to be the coordinator for academic resources. The improvised routines are normal work routines modified to response to the suffering such as Heidi improvisation of her normal routine to give the students affected by the fire emergency loans. The university did not give such loans previously.

The symbolic leadership actions and stories as the donation made by the dean during a formal event and the members who told each other's about this donation.

To sum up, Dutton and al. (2006) theorize that the social architecture (values, routines, and networks) of an organization enhance compassion organizing. The emergent features fuel the compassion process.

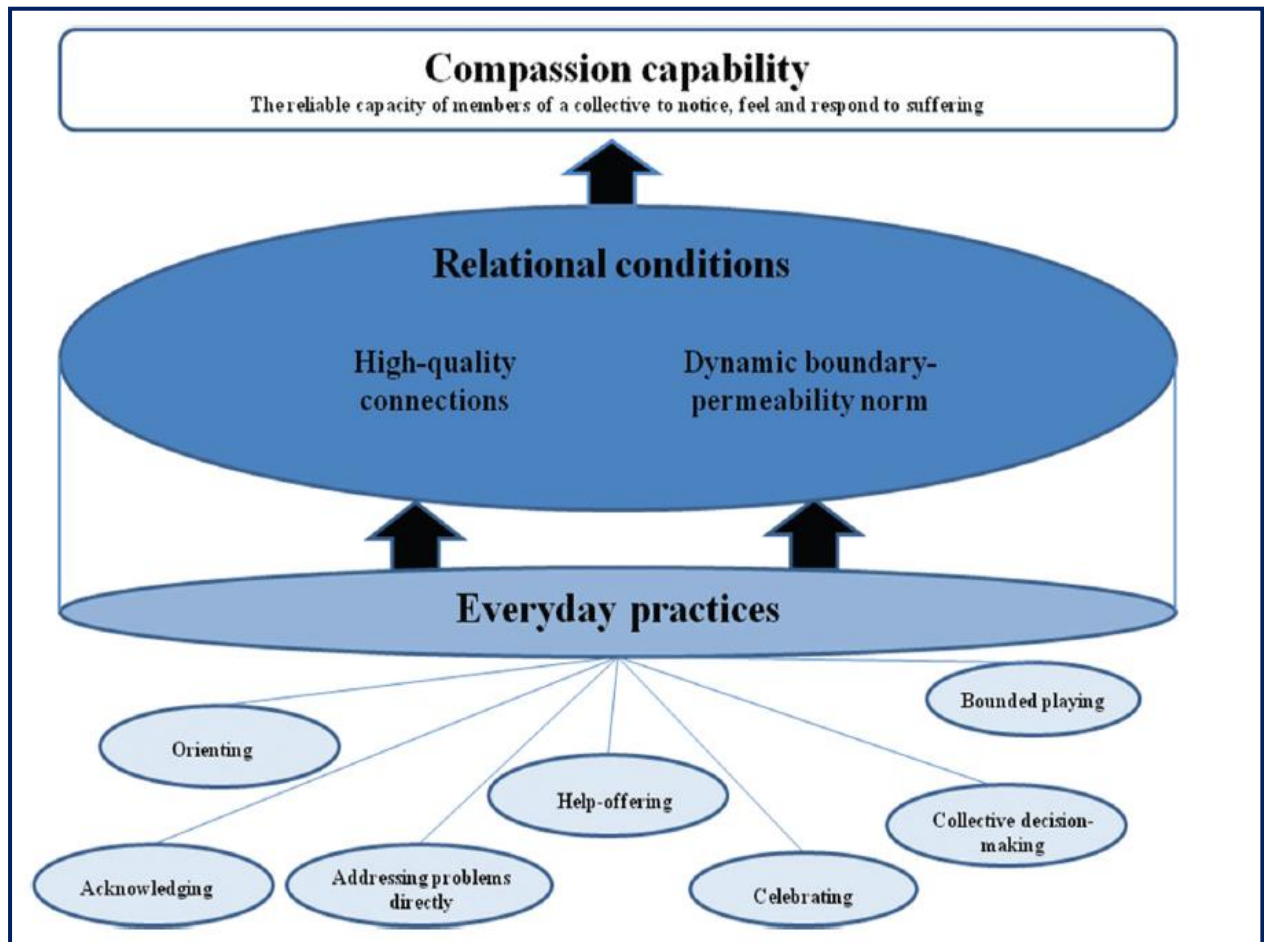
In the below sections, we rely on Dutton et al. (2006) theory in combination with the literature on the values of healthcare systems to analyze the effects of the values emerging from the Lebanese healthcare system on compassion organizing.

To analyze the roles of routines emerging from the empirical data, we referred to Lilius' et al. (2011) inductive model that explain how a set of everyday practices enable organizational compassion.

3.2.1.2. Organizational compassion capabilities

Organizational compassion capability is “the reliable capacity of members of a collective to notice, feel and respond to suffering” (Lilius et al., 2011). The scholars used the term suffering to refer to a wide range of unpleasant subjective experiences, from physical and emotional pain to psychological distress and existential anguish. Their framework explains the foundation of a collective compassion capability through analyzing the daily practices and routine of an organizational unit.

Figure 11 : Lilius et al. (2011) Inductive model of compassion capability



Source: (Lilius et al., 2011)

The everyday practices of an organizational unit create relational conditions that enable organizational compassion. Practices of orienting, help-offering, addressing problems directly, collective decision making, acknowledging, bounded play and celebrating create relational conditions mainly high-quality connections and dynamic boundary permeability norm. These conditions enable employees to collectively notice, feel and respond to the suffering of the members of the organizational unit.

This theory enhances compassion in organizations theories by explaining through empirical data that ordinary practices such as celebrating a birthday of a member can create conditions that enable compassion organization and alleviate the pain of the unit members. The positive effects of organizational compassion are not limited to the suffering only, compassion contribute positively to the performance of the organizations through employees' satisfaction, commitment and low turnover (Lilius et al., 2011; Madden et al., 2012)

Lilius et al. (2011) highlighted the importance of daily practices or routines on the compassion capability of an organization; we would refer to this theory along with our literature on compassion and routines in the healthcare sector to analyze our empirical data in the coming sections.

3.2.1.3.Emergent organizational capacity for compassion theory

Theories on organizational compassion have noted the elements of the social architecture of an organization interact together and enhance the compassion process (Dutton et al., 2006; Lilius et al., 2011). In their study, Madden et al. (2012) build on complexity system theory and propose that compassion capacity can emerge without a formal organizational decision. Madden et al. (2012) define emergence as the development of novel and coherent patterns as a result of self-organization. Self-organization occurs when agents modify their roles in an informal unplanned manner to include compassionate acts like the parents of children with disabilities who played the roles of expert patient and case manager.

Madden et al. (2012) consider organizations as complex adaptive systems. A complex adaptive system is constituted of highly interdependent and interacting agents whose behaviors produce unpredictable outcomes. They identify conditions needed for turning an individual isolated

compassion act into a collective organizational action. Madden et al (2012) theorize that emergent organizational compassion is activated by the pain trigger and it is conditioned by agent diversity, role interdependence and social interaction.

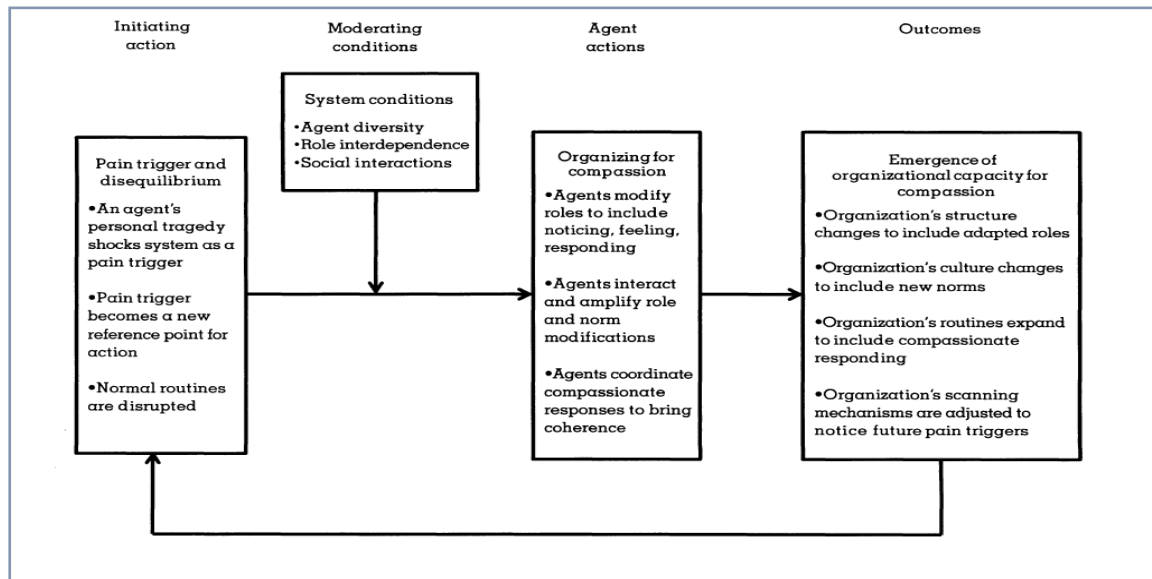
Madden et al. (2012) theorize that the disequilibrium of the system of interdependent agents could lead to the emergence of organizational compassion capacity. They noted that the literature on compassion organizing shows that personal tragedies such as illness, injuries, divorce, disability, or death can affect the workplace. The individual distress can act as jolts that push the system into imbalance. They quote Wheatly (2010) affirming that "once inside the network, this small disturbance circulates and feeds back on itself. As different parts of the system get hold of it, interpret it and change it, the disturbance grows".

The pain trigger can cause system disequilibrium which is the disturbance of daily practices by a member who notices the pain of another and responds to it. Interdependence is the extent to which the roles or processes are interrelated. In interdependent systems, changes in one process or task affect the others. Agents depend on each other's to perform their prescribed roles. Accordingly, they are used to coordinate with each other's regularly; they learn about each other's behavior and feel emotionally connected. Thus, they can notice any atypic behavior or emotion. This interdependence facilitates noticing the pain and organizing compassion.

It is through agent interconnectedness that a member of the organization notices a disturbance in the organization daily practices and routines. They theorize that under specific conditions such as agent role interdependence, compassion can emerge from an idiosyncratic compassionate action to an organizational compassion capacity. This shock or disturbance can lead to changes in roles and thus compassion emerges in the organization. This modification

of role is labelled by Dutton et al. (2006) as created role. If these roles modifications are performed by agent who has credibility inside the network as the dean in Dutton's et al. (2006) case, organizational compassion would be enhanced through what Dutton et al. (2006) recognized as symbolic feature.

Figure 12: Madden et al. (2012) Emergent Capacity Creation for Organizational Compassion



Source : (Madden et al., 2012)

Compassion organizing depends on the individual ability to notice the pain of others therefore noticing the pain is the trigger of the process. Subsection 3.2.2. analyses the behaviors of the participants in light of literature on pain triggers. The scholars also theorized that the activation and mobilization of compassion rely on this social architecture of the organization. Thus subsection 3.2.3. analyses our results in the light of the theories of compassion organizing, organizational compassion capability and emergent organizational capacity.

3.2.2. From unanswered calls for help to compassion oases

To organize compassion, the individual must notice the pain of another person (Dutton et al., 2006; Pirson, 2018). As Kellie, in Dutton et al. (2006) case, who identified one of her students standing up in pajamas outside a burned dormitory. Kellie stopped and knew that the student had lost all her belongings. Since compassion is an innate human response (J. M. Lilius et al., 2011), Kellie triggered a compassion organizing process to alleviate the suffering of her student. The capability of compassion organizing depends on the individual cognitive ability to notice the pain and the emotional capacity to feel another person suffering (Dutton et al., 2006). Thus, compassion organizing is initiated by a signal of human pain. This unexpected suffering is called in compassion literature the pain trigger (Dutton et al., 2006; Madden et al., 2012).

Suffering is the experience of pain that causes an existential grief or sorrow (J. M. Lilius et al., 2008). It is inevitable in human normal lives (Lilius et al., 2011) and it can results from different disruptive events. It could be caused by a natural disaster, a fire, domestic violence, death of a family member, illness or children born with disabilities (Lilius et al., 2008).

The participants in our study stated that they were “*suffering*” from multiple malfunctioning of the system. The suffering is induced at the level of interaction with the providers and at the level of the gaps of the healthcare path and the structure of the system.

At the interaction level, the parents “*suffered*” because the professionals did not listen to their worries and did not encourage them when they faced the challenges. The act of listening carefully to the patients is a compassionate act. As Kahn (2019) theorized that “compassion began with members noticing distress, and then listen closely to people’s experiences.” For

example, participant 2 stated she noticed delays in the development of her son, but the pediatrician refused to admit, she was frustrated, and she was fighting alone. Participants 10,13 and 23 experienced the same problems, the pediatricians did not consider their remarks regarding the delays in the development of their children. The parents asked questions that remained unanswered. These questions are the manifestations of the suffering of the participants. The participants also showed that they need information about the case of their children, they need to know how to deal with them, and they need to know what to expect in the future (participants 2, 10,13, 23).

“Nobody told me that “You” might have delay in walking, maybe mentally, maybe in comportment, maybe in speech We were left alone!!!” (Participant 3)

The participants felt that the physicians *“hide information”* and that the patient *“needs to beg them”* (participant 16) to get the information. Explaining and providing information are identified as compassionate acts (Frost, 1999). In his case study Frost (1999) labeled that act of the nurse explaining to the patient what she was doing as a compassionate act. Thus, here again the parents were expecting compassion from the system vis a vis their pain. In addition, the participants hoped for encouragement which is identified as a compassionate action. In his study, Frost (1999) implicitly related the compassionate action of the nurse to the improvement of the patient. Participants stated that instead of being encouraged, they had to bear the *“negative comments”* (participant 2) of the professionals. The parents were in pain and that is why they were expecting compassion from the system.

During the healthcare journey, the parents become responsible for finding therapists, coordinating between professionals, and commuting between clinics. This journey lacked

compassion responses from the system as one mother said, *“it is a long journey, and there is always something missing”* (participant 17). The parents carry all these responsibilities *“without being helped”* (participant 10) by the system. The parents described searching for professionals as a *“treasury hunt journey”* (participant 1). A father stated that his child needed a cardio-surgery and only *“after a long journey till we found a cardo-pediatrician who could do the operation”* (participant 21). The parents felt distress for being responsible for explaining the medical case of their children as participant 1 explained that *“every time I (she) needs to consult a professional I (she) had to carry son’s medical file, explain his condition using my (her) simple language.”*

“We (the parents) are dealing with something that we do not know. Therapies that we did not know about. There were feelings of anxiety, lack of information.” (Participant 2).

Moreover, the professionals sometimes even refused to talk to each other. As participant 10 explained that *“the challenge now is to make them (the providers) talk to each other”*. The participants felt unsupported in the middle of a crisis. The system did not provide compassionate responses such as referring the patients to providers or providing coordination between professionals. Participant 3 summarized the experience in one sentence

“They gave us this baby and they have all withdrawn.”

The structure of the healthcare system, characterized by its bureaucracy and the financial burden, revealed lack of compassionate actions. Participants (4, 7, 15) explicitly stated that they “suffered” from the bureaucracy. For example, participant 4 had to take her sick son to the offices of the agencies to get approval for tests. She expressed her suffering by shouting

saying: “*You (the employee) didn’t believe us that he is sick, and he needs these tests!!!*” The bureaucracy of the system hindered compassionate actions towards the patients such as facilitating the processes via online approval’s applications or not recommending the physical presence of the patients. The financial burden is another cause for suffering. The inequity of care present in the healthcare system created a feeling of deprivation from a basic right since having an appropriate healthcare is a basic human right. Thus, the suffering of the parents expressed through questions, anger and distress did not initiate compassionate actions.

The scope of the study does not allow us to confirm whether the pain has been noticed by the providers, but the system could not organize a compassionate response or whether the pain was not noticed. However, we feel more tended to consider that the system failed to organize compassion because our data analysis identified some “compassion oases”. Compassion oases are momentary interactions when the member of an organization noticed the suffering of colleague, felt empathetic concern and tried to alleviate the pain (Kahn, 2019). We would use the same term, “compassion oases” to identify compassionate action directed toward an outsider in a system that lacks the capability of compassion. Our data identified some “compassion oases”, for example participant 17 mentioned that one of the therapists “*is my (her) light, let us say my (her) guide.*” Participant 1 expressed that one of the physicians is very supportive, when she consulted him for the first time “*he listened to my explanation (presenting the case of her son), when I finished, he looked at me, smiled and said: now our objective is to enable him to stand up, Keep his file here, I will study the case thoroughly and get back to you. Don’t worry*”. Guiding someone during a crisis, smiling, listening, talking, encouraging and expressing concern are all compassionate responses (Lilius et al., 2008). Almost all participants mentioned similar compassionate responses or “compassion oases”.

However, the Lebanese healthcare system failed to create collective compassion responses or compassion organizing. These findings directed our attention to the role of the social architecture of the system in hindering collective compassionate responses toward the patients.

In the following section, we present the social architecture of an organization capable of organizing compassion according to Dutton et al. (2006) framework and we analyze our results through the lens of this theory.

3.2.3. Boundaries of compassion organizing

Researchers have identified the crucial roles of values, routines, and networks in activating and mobilizing compassion as a response to another's pain. In the following subsections, we analyze the roles of the elements of social architecture of the Lebanese healthcare system in the light of compassion literature and studies on professionals' values, routines, networks, and roles.

3.2.3.1. Depersonalization and detachment shared values

In their theory, Dutton et al. (2006) theorized that values of holistic personhood, expressed humanity, and sense of family enhance compassion organizing. Despite the presence of some compassion oases in the system, our data analysis did not reveal the dominance of these values in the Lebanese healthcare system. One explanation is that the professionals in specific sectors such as firefighting, rescue, police and healthcare are exposed to strong negative emotions on daily basis, thus they suffer from compassion fatigue and try to protect themselves via detachment and depersonalization (Kahn, 2019).

What follows presents some shared values in the Lebanese healthcare system before analyzing how these values lead to a reifying healthcare system (Lazzeri, 2011).

The highly fragmented Lebanese Healthcare system yielding reification

The aim is to study the common values of detachment and depersonalization of the Lebanese healthcare system despite the presence of momentary compassion oases.

Compassion Oases

Our data analysis revealed that values of holistic personhood, expressed humanity, and sense of family unfold during limited and momentary interactions between the parents and the professionals. For example, participant 2 stated that after the diagnosis of the disability of her child, the pediatrician started to ask about the relationship between the siblings. He showed care and concern about the relationship between the members of the family, he did not limit his concern to the disease. He was concerned about the wellbeing of the whole family. Through this compassionate act, he expressed values of humanity and a sense of family.

“Each time, I used to visit him with the boys for a routine checkup or a vaccine, he used to spend more time with me asking about the relation between the brothers.”

(Participant 2)

These compassion oases are dispersed and do not allow collective action. We argue that the inability of compassion organizing might be linked to the detachment and depersonalization, two prevailing values in healthcare organizations. These prevailing values contradict with holiness, expressed humanity and sense of family which are identified as essential for compassion organizing. It may be argued that the absence of collective actions triggered from these oases lies in the fragmentation of the healthcare system in which every healthcare professional works on his/her own with no communication or coordination with colleagues.

Detachment and depersonalization as self-protection

Detachment is a psychological removal of oneself (Kahn, 2019). It involves creating virtual separations between oneself and the person in pain, as opposed to feeling other's pain which is

crucial to the compassion process. Depersonalizing is another form of self-protection whereby the employees depersonalize themselves and others. In order to protect oneself from frequent exposure to other's anguish, these professionals detach themselves physically, cognitively, and emotionally. They become partially absent, and they keep themselves separated from those they serve. Through detachment and depersonalization, the professionals become less capable of getting engaged in empathic actions that need intimacy and connection. Thus, the individuals interacting with them, in our case the patient, perceive them as non-compassionate. Honneth's reification concept refers to the incapability of responding to other's feelings. He defines reification based on recognition and states that: *"we may indeed be capable in a cognitive sense of perceiving the full expression of human expressions, but we lack, so to speak, the feeling of connection that would be necessary for us to be affected by the expressions we perceive."* (Lazzeri, 2011)

The analysis of our results revealed that the lack of values needed for compassion organizing such as holistic personhood are not present. Thus, the treatment was not "whole-patient oriented" (Stange, 2009), but it was more disease oriented. For example, participant 1 stated that after a physician examined her newborn child, he told the parents in firm voice *"if your child survives; bring him back for reassessment. Until that moment, I (the mother) was not aware of severity of his case. I (she) collapsed."* The physician focused on the diagnosis of the disease itself; he did not consider the feelings of the parents and the impact his sentence would have on them. Another manifestation of the lack of compassion is that the parents perceive their voices to be muted. The physicians do not take their comments and information seriously, they sometimes ignore the parents' knowledge of their child's case and do not involve them in the decision process. Participant 8 expressed her feeling that the professionals are not

compassionate by stating: “*you (the therapist) will sit with her for a quarter of an hour, but I am living with her my whole life.*” Faced by the lack of compassion, the patients perceived the professionals as “*rude*” (participant 9).

A reifying system

In his study, Kahn (2019) stated that some types of work expose the employees to intense emotions. Healthcare professionals, firefighters, social professionals regularly face pain and suffering in their daily work. Sometimes the situation imposes distress, humiliation, and tragic events. These situations overwhelm their capabilities therefore they ignore the others in order to protect themselves (Kahn, 2019).

The healthcare system is still dominated by detachment and depersonalization, these values are more present in fragmented healthcare systems (Stange, 2009). . Sir William Osler recognized the importance of considering the wholeness of the patient “*the good physician treats the disease; the great physician treats the patient who has the disease*” (Stange, 2009).. Therefore, we argue that depersonalization and detachment are induced by a self-preservation response

We theorize that the absence of holistic personhood holistic, expressed humanity, and sense of family values hinders organizational compassion. We also argue that highly fragmented systems are dominated by values of depersonalization and detachment. Thus, highly fragmented systems lack compassion organizing.

Whether the lack of compassion is due to an individual who did not notice the pain, or to the fragmented healthcare system common values, the patient perceives the lack of compassion in

the wake of pain as an aggressive individual act or as representation of the values of the system (Lilius et al., 2008).

3.2.3.2. Routines and practices as activators and mobilizers of compassion

Researchers identified the importance of the routines and practices in activating and mobilizing compassion (Dutton et al., 2006; Lilius et al., 2011; Madden et al., 2012). Dutton's et al (2006) identified customer service routines, civic engagement, harm notification and hospitality routines as crucial to noticing of the pain and responding to alleviate it. Lilius et al. (2011) theorize that some every day practices enable creating a collective response to alleviate the pain of a member of a unit inside an organization. These daily practices are orienting, help-offering, addressing problems directly, collective decision making, acknowledging, bounded play and celebrating. While Madden et al. (2012) build on these two theories to note that the interdependency of agents is one of the conditions that allow self-organization of the members of an organization and might lead to the emergence of compassion without a formal decision. Thus, we argue that the absence of interdependency in highly fragmented healthcare systems enables non-compassionate systems to exist.

Our analysis of the data did not identify these routines and practices, on the contrary they showed a clinical review structure and bureaucratic routines that consolidate and reinforce fragmentation. Thus, we referred to the literature to find out the effects of the routines and practices that emerged from the data analysis on the fragmentation of the healthcare system.

In the following part, we present the roles of Lebanese healthcare system common routines and practices. Then, we analyze the effects of absence of routines, practices and conditions that enhance organizational compassion on this system.

Lebanese healthcare system dominant routines and practices.

Our analysis has showed that the Lebanese health care presents a clinical review structure and bureaucratic routines. Both identified aspects contribute to the fragmentation of the system and will be discussed in the section below.

Clinical Review structure, an obstacle to organizing compassion

A clinical review structure supports focusing on a single task to develop objective and unemotional assessment of a specific case. Kahn (2019) argues that the adjective clinical in this case has two meanings ; the content of the review of the medical case and the objective unemotional tone of the review. This routine fueled by the values of detachment and depersonalization might be an obstacle to organizing compassion.

Our results reveal that the medical interferences of the physicians are ruled by the clinical review routines. One example, participant 9 stated that the physician diagnosed the case saying, *“your son is paralyzed, he won’t be able to control his urinary or bowel system and he would die at 7 years old.”* The mother was *“hurt”* and maybe traumatized by the objective unemotional disclosure of the case. As a result, the mother perceived the behavior as non-compassionate; Integration of psychology session in the curriculum of medical students, as it is the case in the French system for example, could be a solution to overcome this problem.

Bureaucracy of the healthcare system as a limit to compassion

In addition, the bureaucracy of the healthcare system limits the capacity of compassion in healthcare organizations (George, 2013). These practices focus more on applying the rules than on human suffering. They tend to manage depersonalized cases rather than human beings and

they do not keep a room for the human agency to develop solution (George, 2013; Pirson, 2018). Adherence to bureaucratic routines might inhibit compassion organizing especially in times of crisis. For example in their study Shepherd and Williams (2014) noted that bureaucracy led to waste of donated items.

Some manifestations of this bureaucracy are the coverage schemes, and more specifically their approval request processes and regulations. An illustration of this situation is that of a mother requesting coverage for the hearing device of her child. She spends hours at the public insurer office, and she was obliged to have her son with her.

“They (the employees of the public insurer) wanted to see my child, so we have to take him, to wait half a day, with him crying, so to check him and to cover 80% from the most basic hearing aid as per their estimated price, which is nothing” (Participant 15

Another child needs physiotherapy on a daily basis but the insurer refused to cover more than 30 sessions per year:

“The neurologist asked for physiotherapy sessions but later it became too expensive. The sessions are not covered nor fully reimbursed. The public insurer reimburses 12,000 LL out of 35,000LL after 4 months. The insurer reimburses only 30 sessions per year. And her case needs a session every day!” (Participant 24).

A third example is that of a dentist who insisted to perform dental care procedures for a child with developmental disability inside a clinic and refused to listen to the mother who was clarifying that in order to perform this procedure her son should be under full anesthesia. The dentist kept on refusing to customize the provision of care because the child's insurance

company refuses to cover such procedures other than on the dentists' clinics and not in hospitals (participant 2).

The rigid bureaucratic processes dominating the Lebanese healthcare system negatively affected the perception of the quality of care. Based on the presented empirics, we might argue that healthcare professionals use clinical review and bureaucracy to depersonalize the patient and subsequently protect themselves from pain. They are reifying their patients.

Reifying patients

Our analysis shows that the system lacks Dutton's et al. (2006) routines and Lilius' et al (2011) practices and Madden's et al.(2012) system moderating conditions. In the following part, we study the conditions that discourage organizational compassion from these perspectives.

Dutton et al (2006) theorize that routines such as civic engagement, service provision, notifications and hospitality enhance compassion activation and mobilization.

Our analysis suggests that the system does not provide a routine similar to the student provision or Global citizenship which guaranteed spreading the empathetic concern and providing donations as in Dutton's et al. (2006) case. Though, it is recognized that non-governmental organizations in Lebanon help families to cover the cost of some assistive devices, participants mentioned that they were not oriented toward these non-governmental organizations. that As one mother explained, she was informed through a friend and not through the healthcare professionals about a non-governmental organization that helps families in financing assistive devices (participant 4). This is how she could provide it to her son who needed such a device and which she could not afford. The system does not have a normal routine similar to the email

routines in Dutton et al. (2006) by which the university members communicate with others or notify the members of the university of a harm. The system lacks a referral routine; the providers do not communicate with each other normally. The participant has to become the coordinator in this fragmented system. There is no communication tool among the healthcare providers.

We argue that the providers might not be aware of the presence of such assistance because there is no routine of guiding patients throughout the system. The system constituted of providers, financiers, and regulators is therefore highly fragmented.

Lilius et al (2011) identify orienting, help-offering, collective decision making as practices that enhance compassion capability of an organization.

Our analysis highlights that such practices do not exist on large scales as we previously mentioned though the data reveals some “compassion oases”. Some participants mention that the professionals sometimes guide them inside the system, for example an orthopedic surgeon orients a patient to a dermatologist, but it is not a common practice it is an idiosyncratic response (participant 1, participant 3. participant 4). Other parents state that they are involved in decisions related to their children’s cases. For example, participant 2 explained that she and her son’s pediatrician prepared a list of tests needed for the diagnosis of her son’s case. Participant 12 also emphasized that the parents and the therapist discussed and agreed on the treatment of her son before implementing it. Such examples are limited as we consider that Lilius’ et al. (2011) practices mainly orienting, helping offering and collective decision making are not common daily practices. The participants search for services and providers inside the system, and the providers do not offer help during the care path. As participant 4 explained that

when her son needed to be transferred to another hospital that provides the treatment he needs, she looked for a hospital specialized in her son's case, she contacted that hospital to guarantee the admission of her son, she explained his critical medical case to the medical staff there and she accompanied him in the ambulance. Although this participant had not explicitly stated that the professionals had "all withdrawn" as did participant 3, her voice tone indicated the negative emotions that she experienced during that moment. Participants also complained that they were not involved in the decision. For example, participant 27 explained that the hospital decided to release her son home without discussing this decision with her. At that time, her son was a newborn baby that required intubation to be fed and she was not trained to perform this delicate task.

The participants expressed their dissatisfaction of the quality of care; some blame the professionals for not orienting them inside the system, offering help in finding a provider, training them to perform needed tasks, or getting them involved in the decisions. The participants expected Lilius's et al. (2011) practices and failed to find them most of the time.

We argue that the absence of these routines and practices diminishes the organization's compassion capabilities and hinders organizational compassion.

These characteristics of the Lebanese healthcare system hence could not allow collective actions of compassion. The third element of this social architecture is networks.

3.2.3.3. Networks as feelings, interpretations, and action transmitters

Studies on compassion organizing highlight the importance of the organization members' networks (Dutton et al., 2006; Madden et al., 2012; Pirson, 2018; Shepherd & Williams, 2014).

Compassion organization is enhanced when the members of networks have access to different types of resources and can direct them toward lessening the pain (Dutton et al., 2006; Madden et al., 2012). Networks impact the activation and mobilization of compassion organizing. They transmit feelings, interpretations and action calls, they are critical in extracting and calibrating resources (Williams & Shepherd, 2018). They also enhance the credibility and trust in the message sender which improves noticing the pain trigger and responding to it. If the sender belongs to multiple networks, then propagating the pain trigger is improved and accessing multiple resources is easier (Madden et al., 2012). These studies have focused on noticing and responding to the pain of members who belong to the same network. Our study identifies that despite individual compassionate actions, these actions failed to become a collective compassion action. We referred back to the literature and we noticed that the researchers called for more researches to understand the ability of organizations to alleviate the suffering of a non-member (Madden et al., 2012). We identified Shepherd and Williams' (Shepherd & Williams, 2014; 2018) study on the importance of local community in noticing and successfully responding to the pain. Shepherd and Williams (2014) theorize that local community has a better performance than non-local communities in noticing and responding to pain. Building on this theory, we analyze the failure of compassion activation and mobilization as a response to the pain of the participant.

In the following part, we present first a summary of Shepherd and Williams (2014) theory focusing on the role of networks in local venturing, then we analyze the role of network in noticing and responding to the pain of the participant thru the lens of this theory.

Local versus non-local venturing in organizing compassion

Through their study, Shepherd and Williams (2014) extend the literature on the role of the network in compassion organizing. They identified the critical role of localness in organizing compassion to reduce the suffering after a natural disaster. Their theory, an extension of the compassion organizing theory, stressed the importance of local community values, local community knowledge, and local community networks. They concluded that the pre-existing relationship among the individuals and the knowledge of the community resources are highly effective in noticing pain and customizing resources to meet victims' need through local venturing. Shepherd and Williams (2014) stated that "to enact compassion organizing, organizations recognize members impacted by traumatic events generally due to pre-existing relationships or connections."

Local community has been a better performer than the non-local ones. The local community members share local values, know the local resources and routines, and have existing relationships with each other. Being a local increases credibility and trust in the individual. The scholars compare local venturing to non-local venturing. They theorized that locals share values that influence their identity and facilitate decision-making process. They share local history, social relationships, individuals' skills, and capabilities. This local knowledge is a tacit and informal knowledge, and it is difficult to transfer it. The study stresses that local relationships are important resources for local ventures. These relationships are the networks of friends, family members, and other members inside a community. These relationships are strong ties that enhance trust, enable the sharing and transferring resources, coordination of the tasks. Thus, local community members can succeed in organizing compassion to alleviate the

suffering of their suffering even when the community itself is victim. On the other hand, the non-locals' compassionate actions are interrupted by the lack of physical (geographic, logistics) and social (leadership groups) knowledge. Thus, researchers working on compassion organizing concur on the vital role of networks. Being a member of local community means belonging to a local network, therefore we will analyze the effect of the network on compassion activation building on this theory.

Compassionate and unhelpful providers

The healthcare professionals in the Lebanese healthcare system are liberal professionals working in private clinics or healthcare organizations. Through the analysis of our results, we concluded that the networks of the healthcare professionals are limited to other professionals who are members of the same healthcare organization such as hospitals or university hospitals. Being part of an organization network caused two contradictory responses: compassionate and non-compassionate.

A compassionate response example

For example, participant 1 explained that when her child needed a dermatologist before his spine surgery, the orthopedic contacted a dermatologist who worked in the same hospital and introduced the case of the patient and coordinated with him. The mother described this physician as "*a good and caring physician.*". We argue that the physician noticed the distress of the mother who needed a dermatologist. He felt her suffering despite being an outsider to the network. He had pre-existing relationship with the dermatologist who was a member of the same community or network. He knew the capabilities and skills of his colleague. He trusted his performance. Therefore, he improvised a routine and coordinated with him. An improvised

routine in compassion organizing is a normal work routine that is spontaneously modified to answer a pain (Dutton et al., 2006). We label this action as a compassionate response.

An unhelpful provider example

In another scenario, the same participant explained that when a second physician recommended speech therapy treatment for her child, the physician did not refer her to a therapist; thus, she had to search for one. She described him “*unhelpful*.” We argue that it might not be due to the human agentic factor which is noticing and feeling the pain that the second physician behaved in a uncompassionate manner. We also argue that due to the fragmentation of the healthcare system, the second physician does not belong to a network that he can mobilize. The medical and the socio-medical providers belong to different networks. If the physician operates in an organization that does not provide socio-medical services, then he lacks the physical and social knowledge of the community of the socio-medical providers.

It appears that the absence of network diminishes the compassion organization capability of a system. This leads us to investigate whether the roles of healthcare professionals affect compassion organizing.

3.2.3.4.Roles as potential favorable system condition

Roles are the organization’s goals and aspirations (Madden et al., 2012), they represent the expectations of others from a specific individual in the organization. Roles belong to the organization and not to the individual, and agents might change their roles over time (Madden et al., 2012).

Compassion organizing literature identified the interconnectedness of the agent roles as a favorable system condition (Madden et al., 2012). As a common practice in abductive research, we referred back to the literature on the organizational role of healthcare providers. Halls (2005) stated that healthcare professionals have different beliefs, attitudes and behaviors which would create a barrier to interprofessional teamwork. Mintzberg (1993) theorized that healthcare providers operate in a special structure that he labelled, professional bureaucracy. This structure is common in hospitals, schools, universities, and social-work agencies and is characterized by complexity which is embedded in the interdisciplinary nature of healthcare activities.

This led us to confront our empirical data against Mintzberg's professional bureaucracy structure to analyze how the specificity of this structure is affecting the compassion organizing processes.

Our empirical results revealed that even though the professionals work interdependently, they are however, not used to coordinate. As one mother explained "*the challenge now is to make them (therapists) talk to each other*" (participant 10).

This is fragmentation, lack of communication and coordination are characteristics of professional bureaucracy structure such as healthcare organizations. This is a structure that relies on the skills and knowledge of the professionals who are expected to produce highly standardized services (Mintzberg, 1993, pp. 189–214). In such structures, professional coordinate through the standardization of skills, each professional knows what to expect from his colleague. The professionals hired for the operating core of the organization are duly trained and indoctrinated specialists and they have control over their own work. Having considerable

control over their own work gives the professionals considerable independence over their colleagues. In this structure, professionals do not consider themselves part of a team instead they perceive the organization as the place where they practice their skills (Mintzberg, 1993, pp. 189–214).

Another explanation of the lack of coordination might be the pigeonhole process of the professional bureaucracy. The pigeonhole process takes place when the professionals divide the patients in groups according to their disease and operate freely inside their own pigeonholes (Mintzberg, 1993). Thus, the professionals focus only on the organs they are treating and not on the holistic human being. They coordinate through standardization of skills, and they resist cooperation, which is one of the major difficulties in professional bureaucracies.

Such a system poses major difficulties when dealing with persons with disabilities whose treatment requires interventions of multiple healthcare providers and does not fit inside one pigeonhole. Professionals resist cutting across pigeonholes because they are used to work freely inside their own pigeonhole.

Based on the above, we can argue that the professional bureaucracy structure of the healthcare organization relies on standardization of task and pigeonholing. These characteristics make the roles of the professional disconnected, and when the professionals tasks are not interdependent, the workers are less likely to get involved in compassion organizing processes (Grant & Patil, 2012; Madden et al., 2012). Having the bureaucracy structure inside a private profit-oriented healthcare system such as the Lebanese healthcare system, the problem of fragmentation is intensified. As private profit oriented healthcare system is considered by Mintzberg (2018)

more as a collection of disease treatments and not a system which means that the healthcare providers are more disconnected from their peers functioning in non- profit oriented settings.

3.2.4. Absence of the relevant social architecture as a hindering factor to organizing compassion

The agentic reaction of noticing the pain, and the absence of the social architecture hindered organizing compassion. This corroborates our findings on compassion organization as shown by our empirical data.

First, we presented that the values of detachment and depersonalization widely used by healthcare professionals constitute a main barrier to compassion process since noticing and feeling the pain are the trigger of the process. Without a noticed pain there is no compassion; compassion organizing is irrelevant if the individual fails to notice the suffering of another person (Pirson, 2018). Unfortunately, in a non-compassionate system, the professionals find themselves busy in unconscious self-protection processes and unable to notice and respond to the suffering of an outsider. Instead of launching a compassion organizing process, they become involved in distress organizing process (Kahn, 2019). Distress organizing could be considered as an opposite to compassion organizing. Distress organizing is a collective mechanism and interpersonal patterns of behavior used by system members to avoid noticing an unbearable experience of distress. This process involves avoidance mechanism and lack of interpersonal relationship (Kahn, 2019). The distress organizing processes empower the routines (clinical review and bureaucracy) of the healthcare system. The lack of interpersonal relationship required for organizing distress leads to the limited role of the network in healthcare system. Based on our previous elements, we suggest that the absence of routines of

engagement and lack of networks prevent compassion organizing. Finally, the dominance of pigeonholing processes in professional bureaucracy structures such as the healthcare system gives no room for role interdependence and blocks organizational compassion.

Summary of chapter 3

Our empirical data reveals that the Lebanese healthcare system is characterized by inequity of care and lack of compassion organizing. We analyzed the inequity of care by referring to Levesque et al. (2013) framework and we concluded that the Lebanese healthcare system shows inequity of care.

Our analysis of the lack of compassion organizing through the lens of three theories: Dutton et al. (2006), Lilius et al. (2011) and Madden et al. (2012) allows us to conclude that the characteristics of the Lebanese healthcare system do not facilitate or allow compassion organizing.

Summary of Part I

This part has presented the challenges caused by a fragmented healthcare system to parents of children with disabilities.

We have objectivized the failures of the highly fragmented system in responding to the needs of the families of children with disabilities. Then, we have provided a concrete expression on the inequity of care of the system before explaining the roots of the lack of compassion in a highly fragmented system. The absence of compassion in the wake of pain and inequity is seen as aggressiveness toward the sufferer (Lilius et al., 2008).

Part II-Emerging Solutions

The Lebanese highly fragmented system is a type of system whereby the parents feel that they have no choice but to assume the role of experts in aspects of their children' health (Gómez-Zúñiga et al., 2019).

This part presents the solutions adapted by the parents to surpass the challenges. It is divided in three chapters. Chapter four presents the solutions adapted by the parents at individual level. And the collective organizational solution created by the participants. Chapter five analyses these findings in the light of grief, resilience, knowledge brokering theories and compassion organizing.

Chapter 4-From individual to collective organizational success stories: moving from decision to solution drivers

The analysis of the interviews revealed that some parents managed to find solutions to the problems encountered using available resources. Parents educated themselves on the condition of their child, benefited from prior experience and knowledge, mobilized their network, and became the decision maker. They were able to propose solutions to overcome the challenges they were facing in the highly fragmented healthcare system. This chapter is divided into two sections . Section 4.1 presents the solutions individually adapted by the parents to respond to the needs of their child. Section 4.2. presents the collective organizational solution realized by four participants who decided to solve their individual problems as well as the challenges faced by other families having similar situations.

4.1. Individual solutions

4.1.1. Parents capitalization on prior knowledge

The education level of the parents is a main facilitator because it enables them to search for the information needed and to understand it. They felt that their education level allows them to make “*right decisions*” regarding the case of their children as one mother stated:

“We are knowledgeable, so we knew what to do. she is strong but we are well – informed parents. I have my own experience and knowledge... When you have your own experience, you will not let anyone direct you or influence your decision especially.”
(Participant 22)

Another participant said:

“...I am not naïve, I don’t believe whatever they say, for example one of the most famous orthopedics in Lebanon told me that he can make my son walk but I don’t believe him ...I know that spina bifida means that the nerves were not developed.” (Participant 24)

The parents relied on their prior “*knowledge*” (Participant 22).

4.1.2. Searching for relevant additional knowledge

Faced by the absence of information either because the professional did not disclose the information properly at the discovery of the disability or because the professionals have limited information about the case; the parents sought information. The parents relied on different sources of information such as the internet, books, conferences, and other families.

The web is a widely used source of information; that is easily used and accessible.

“I remember spending nights on my computer surfing the internet for the meaning of these medical terms and the symptoms of these diseases or syndrome” (Participant 1)

Books are another source of information, a mother complaining about the absence of information stated:

“I do lot of research. First, when it is not clear, I bought lots of books. Otherwise, who would guide you or advise what to do...I started to read books stating that contact with the nature is very beneficial, that accompanying her to the supermarket is also beneficial, to make her aware of the surrounding. Who would tell you so? the psychologist would tell you a phrase not more. Nobody would tell all these details, I educated myself on how to deal with her, what would calm her down. I learnt lot of information from the books I read.”. (Participant 5)

Some parents assisted to specialized conferences on disability where they met other families and exchange information.

“I had met a lady in one conference she told me about her nephew, who is living abroad, is autistic but he was full integrated and well performing.” (Participant 10).

4.2.3. Network mobilization as a mean to access information

Parents were faced with the lack of information and support. They did not know what to do and where to seek help or advise. Therefore, they decided to mobilize their network. An example is a mother who is a researcher in public health:

“I did not know what psychomotor therapy was about. I visited the department of psychomotor therapy on the university campus. I asked the director, a colleague of mine, to explain what psychomotor therapy is and in case my son needed this type of therapy. I asked where I should go, what should I do. I used to ask people, friends, doctors that I knew, people who had a family member with a certain type of problem (here it meant handicap or special needs). That’s what I was doing”. (Participant 2)

Another example of a mother who explained that she benefited from her professional network.

“As a teacher, I have a wide network and it is a plus. In Lebanon it is mouth to ear; when you present your problem lots of people give you names, suggestions, advice, names of physician etc.” (Participant 24)

A participant explained that when her son needed speech therapist; she had to ask her friends and colleagues if they knew any therapist and she is the one who presented the condition of her son:

“We were asked to consult a speech therapist. It was the first time I heard that word. I did not know where to find one! Another treasure-seeking journey began. I started to ask friends, colleagues, and family members until I reached one”. (Participant 1)

Some parents were supported by their social networks such as a family member, a classmate, or a colleague. One father explained.

“My son needed a cardio-surgery. It was a long journey till we found a cardio-pediatrician who could do the operation. My sister-in-law worked at a hospital, and she guided us through the system.” (Participant 21)

A mother was guided by her ex-classmate. The latter, a mother of a Down Syndrome daughter, knew and volunteered to guide the participant through the care path.

"A friend of mine, an ex-university classmate, called me and said I knew you got a trisomic baby and my baby girl is trisomic as well. At that time, my son was 18 months old, and her daughter was 28 months. She told me about the psychomotor treatment she started for her daughter, and we started then one will guide you to another ..."(Participant 6)

Other parents benefited from the media to ask for help to finance an assistive device or to find a cure. For example, a mother asked for help during a documentary broadcast on children with disabilities.

"The physiotherapist told me that he would be able to walk if he uses an assistive device. I asked about the costs and where to find them, I knew that they would cost between 3000\$ and 4000\$ and frankly I could not afford them... I gave up. Till one day, a colleague saw me by chance on the news doing a report on the schooling difficulties for persons with disabilities. She volunteered to help. She knew somebody at one of the NGOs who produces these kinds of devices. She put me in touch with him and so was it." (Participant 4)

4.2.4. From accumulating of knowledge to decision making

The system lacked a support unit or a referral. With time, the parents educated themselves about the case and they accumulated the knowledge till almost saturation. At that moment, they felt confident about their decisions.

“First, the specialized persons were the decision’s makers because I believed that they are the experts and I do not know what the word means. Then, you realize that they were not, thus you start to educate yourself on the case and you became the expert. Thus, you start to make the decisions” (Participant 2).

As one mother explained:

“Now, I know where I should go, I know.” (Participant 7)

In conclusion, this section has presented the solutions implemented by the participants to solve their individual problems.

The participants complained about the quality of care. They have found themselves lost inside the maze of the fragmented healthcare system without a support team or a reference, with an absence of information, and with multiple financing schemes. They are entitled to make a lot of choices. They are supposed to choose whether to use private or public healthcare services, who to consult about their child’s condition, what services to utilize socio-medical therapy, surgeries, and medications. The choice is not an easy task in a complex healthcare system such as Lebanon where there are multiple private and public providers, and the complexity turns the healthcare system more into a maze, a system that requires more than a map to be navigated successfully (Collyer et al., 2017) and the success depends on the resources the individual can collect during the “journey through the maze”(Collyer et al., 2017).

The participants relied on their prior knowledge and sought the knowledge relevant to the cases of their children. They mobilized their network to extract information and support. When they

became self-confident, they started to make decisions related to their children's treatment by themselves.

4.2. Collective organizational success stories: moving from decision to solution drivers

In the previous section, we focused on the individual solutions adopted by the participants to answer the needs of their children with disabilities. This section presents the innovative collective solutions developed by parents of children with disabilities. These examples illustrate how those parents became drivers of change and how they go beyond their own needs to provide global community solutions.

The examples chosen will be presented as narratives based on parents' shared experience. The narratives follow a chronological order that starts with the disclosure of the disability and ends with the solution implement.

4.2.1. From person-centered solutions to community-oriented inclusion

Below is the narrative of participant 2 who is a mother that has created a socio-medical center inside a school and an inclusive university program. The mother presents how the disability of her son has been diagnosed, the care path, and how the ideas of the socio-medical center and inclusive university program emerged.

“He is my second son. I had a normal delivery... Later, I started to notice that he was not acting nor interacting the way his brother used to do. I expressed my worries to the pediatrician, but he was not convinced. I started to ask my family members, friends, colleagues, or acquaintances who have a family member with special needs about physicians who are experienced in child developmental issues. Lead by my intuition, I decided to start a psychomotor treatment. I did not know what psychomotor therapy was about. I visited the department of psychomotor therapy on the university campus (where the mother works).

Psychomotor and speech therapy treatments started at a university socio-medical clinic. Later, the department (clinic) was unable to provide me with the services due to internal regulations. I shifted the treatments to private clinics offering these services. I tried to have both services in one clinic in order to facilitate the coordination among the providers.

I re-expressed my worries to the pediatrician in a firmer tone. I told him that there is something wrong and I want to conduct further diagnostic tests. Through my social and professional networks, I investigated the needed diagnostic tests, and told the physician that I need to do this test and that test. We have done all tests that might come in mind,

whenever any doctor or physician proposed a test, we perform it, we repeated the genetic test, we have done an MRI ...I was struggling alone, I felt frustrated...I am the mother and I know. I want to investigate more, I need answers. I am not insane, I am dealing with him every day and I know, I have another child and I know how things should be. The pediatrician was not convinced till he saw IQ tests results that showed delays. At the age of four years, I travelled and consulted a developmental specialist abroad. I got a defined diagnosis of the case which is dyspraxia.

Back to Lebanon, the socio-medical treatment continued, I coordinated among all the service providers (psychomotor and speech therapists and the pediatrician).

He (the child) was admitted to an inclusive school. A team provided the treatments during school hours. But he needed extra sessions, he used to have them during the afternoon in a private clinic. I coordinated among the providers!

In summary, each stage had its difficulties. The first stage was tough because I was discovering something completely new...Till today, nobody has been able to tell me what to expect or to explain the case. Maybe I will tell them what to do and what to expect in the future. We are the parents, and they are the professionals. "They" should be the knowledgeable ones while "we" the parents are driven by emotions and not science. We are dealing with something that we do not know. Therapies that we did not know about. There were feelings of anxiety, lack of information. I was not prepared to have a child with a disability. I am alone, I do not know what to do and I have to make decisions because the child is a human being, and he has needs that cannot wait. You find yourself in the middle of a struggle to advocate child rights.

New words, new terminology, new actors, then you find yourself as the KEY actor, you become the expert while they should be, they should know who does what. First, you let the specialized persons to be the decision makers because you believed that they are the experts. Then, you realize that they are not, thus you start to educate yourself on the case and you become the expert. You start to take the decisions on what to do because you position yourself as the decision maker and the expert.

The Lebanese system revealed lot of gaps and challenges which makes you (the parent) the expert. During those years, I acquired a lot of information and expertise. I thought of helping other families who have children with disabilities. Therefore, I contacted some colleagues, families with children with disabilities, professionals in the domain of disabilities who have common objectives of helping others. I proposed the creation of an NGO. Its mission would be promoting awareness towards the needs of PWDs, fostering their inclusion in society and facilitating the coordination of their care. Through the NGO, we financed many projects to date. Some of them are the adaptation of public gardens to be accessible for children with disabilities.

Then I had the idea that creating a socio-medical services center inside my son's inclusive school would facilitate the everyday life of parents of students with disabilities. Students who have disabilities need additional therapy sessions after their school hours. I know how tiring it is to coordinate between providers and to commute between geographically disperse clinics. This center provides socio-medical services inside the school premises. Thus, the parents would be relieved from the burden of transportation, and the inconvenience of coordination. Their therapists would provide the session inside the inclusive school.

When my son reached almost 14 years old, I started to worry. Inclusive schools in Lebanon accept to enroll children with disabilities till they reach 16- or 17-years old maximum. Afterward, the parents of these young persons with disabilities have one of two choices. Either their children would stay at home doing nothing and they will forget what they have learned, or they would admit them to specialized institutions. I have always struggled for inclusion; how would I accept to enroll my son in a specialized institution or to make him sit at home; which means exclude him from society. I told myself there should be other options...I had the idea of starting a university program customized to the need of these young individuals (persons with disabilities). Being a university professor, I contacted the university board, and I pitched my project... they accepted the idea, but we need to sort out the legalities of the program. Universities need to get the ministry of education on programs launched. For students to be admitted to the university, they need an official baccalaureate. Students with disabilities do not have an official baccalaureate. To solve this problem, we had recourse to a faculty that provides unconventional programs, and this faculty is not under the umbrella of the ministry of education. This faculty provides certifications of attendance and not a license. Having sorted out the legalities, I shared the idea of the members of the NGO and the project is launched. We called specialists that I know to discuss the implementation of the idea with them, we recruited specialists in special education to create a customized curriculum. We contacted families, that I know, who have young individuals with disabilities to encourage them to enroll their children.... I follow up the performance of the project.”

To highlight the main events in participant 2 experience, we list them in table 12 below.

Table 12: Main events of the narrative of participant 2

Main Events	Description
1	<i>I told him that there is something wrong and I want to conduct further diagnostic tests.</i>
2	<i>I was struggling alone, I felt frustrated There were the feelings of anxiety You find yourself in the middle of a struggle</i>
3	<i>I re-expressed my worries to the pediatrician</i>
4	<i>nobody has been able to tell me what to expect or to explain the case.</i>
5	<i>you start to educate yourself on the case</i>
6	<i>You start to take the decisions on what to do because you position yourself as the decision maker and the expert you find yourself as the KEY actor</i>
7	<i>I know how tiring it is to coordinate between providers and to commute between geographically disperse clinics When my son reached almost 14 years old, I started to worry... Inclusive schools in Lebanon accept to enroll children with disabilities till they reach 16- or 17-years old maximum</i>
8	<i>I had the idea that creating a socio-medical services center inside my son's inclusive school would facilitate the everyday life of parents of students with disabilities. I had the idea of starting a university program customized to the need of these young individuals (persons with disabilities)</i>
9	<i>I pitched my project... they accepted the idea</i>
10	<i>We need to sort out the legalities of the program We called specialists that I know to discuss the implementation of the idea with them,</i>

Source: Prepared by the author

4.2.2. Creating a holistic care center for autistic children

Participant 10 is a mother who could not find an inclusive school for her son with disability, therefore she decided to create one. The below narrative follows a chronological order of the main key events.

“He is the youngest child in a family of three children. At the age of 6 months, he had a large head curve, and he could not hold his head properly. The tests and the IRM results were normal. At the age of one year, he could not do what his siblings used to do, he does not play well, he does not make proper eye contact. I noticed the delays and started to believe that there was something wrong, I know I have older kids! At 14 months old, I was admitted to a nursery and asked about his performance frequently. The answer was that he was not part of the group. My worries increased with time, so I started to consult several physicians...

They said that boys usually experience delays and there were no signs of abnormalities. I was not convinced, I started to read, to search the internet, and to attend conferences on developmental delays. The physician insisted that he is fine, but he added “it is OK”; let him have psychomotor therapy sessions. At the beginning it was a mobility deficiency, he could not walk, nor hold his head. This was my first contact with a professional and it would be better not to talk about my suffering! She (the therapist) was not so good. Somebody referred me to her. Her clinic was on the 8th floor, sometimes there was electricity, so we needed to use the stairs to the 8th floor, and she used to charge 30\$ for 40 minutes twice a week. It was not cheap. Sometimes I used to climb to the 8th floor to find out that she had forgotten the appointment, so you descend

all the way down. In brief, we realized later that we need speech therapy. As you know, there is no multidisciplinary team. Thus, you cannot have all the treatments in one place. The challenge now is to make them talk to each other. Each therapist wants the other one to coordinate with him/ her: “Let her call me no let her call me and so on” I did not feel any advancement and I kept looking for a diagnosis. It happened that I met a lady in one conference; she told me about her nephew who is autistic and who was fully integrated and performing. He lived abroad. I called his mom, and she advised me to travel there...Concurrently, my son was diagnosed as autistic, and the neurologist also told me to travel today not tomorrow.

My son has dual nationality so we (my son and I) travelled there immediately. He started Applied Behavior Analysis (ABA) therapy in a specialized school in the morning and home therapy in the afternoon. The team used to come home to work with the child and to teach the mother how to deal with her son! (Deep breath, deep sigh). This lasted around 9 months before we had to go back to Lebanon to join the rest of the family.

I started to search for similar schools (organizations providing academic and socio-medical services). I refused to admit him to a specialized institution. I wanted an inclusive school. When I failed to find one, I decided to create one. To be able to do so, I started to look for a group of families interested in my idea. I spread the message till I was able to form a group of 4 families willing to create the program. Since we were looking for an inclusive setting, we decided to look for schools that would agree to host our project. We met with the school director, we explained our idea, a special classroom inside the school premises. He listened to us and answered on the spot: “I know nothing about inclusion nor autism but if you can do something go ahead. I support you. I would

give us a space where we could do whatever we want.” Our children were in their separate classrooms, but they shared sports classes, music classes and other facilities with regular students.

Now that we got a location for our project, we started to prepare everything else: the painting, the parquet in the floor, the educational materials...Some brought stuff from home such as computer, educational toys, books...We trained ABA therapists, recruited the trainers and the therapists. I tried to mime the program exactly applied abroad. The only missing therapy was the one-to-one treatment. Each child had to do individual speech and psychomotor therapies at private clinics after classes. We stayed on this schedule for 6 or 7 years... We asked the therapists for frequent reports, and we imposed coordination...I became stronger...

Later one student turned 14 years old, and another turned 12. So, we created a Functional Academic Skills (FAS) program. The plan of FAS was to train them in daily tasks and prevocational functions such as cooking; going to the supermarket, learning how to pick up their stuff extra; because they reached an end in the academic improvement.

With time the awareness regarding Autism and special needs increased. The school started to accept students with disabilities, the classroom of autistic students turned to be under the school management.”

Table 13 below summarizes the main events of the experience of participant 10.

Table 13: Summary of main events of the experience of participant 10

Main Events	Description
1	<i>I noticed the delays and started to believe that there was something wrong, my worries increased with time, so I started to consult several physicians</i>
2	<i>The physician insisted that he is fine... I kept looking for a diagnosis.</i>
3	<i>...my first contact with a professional and better not to talk about my suffering!</i>
4	<i>I started to read, to search the internet, and to attend conferences on developmental delays.,</i>
5	<i>The challenge now is to make them talk to each other there is no multidisciplinary team</i>
6	<i>(abroad the child was) in a specialized school in the morning and home therapy in the afternoon</i>
7	<i>I started to search for similar schools ...but failed</i>
8	<i>I decided to create one</i>
9	<i>We look for schools that would agree to host our project</i>
10	<i>We started to prepare everything else. We trained ABA therapists, recruited the trainers and the therapists.</i>

Source : Prepared by the author

4.2.3. Developing of information disability hub inside a pediatric ward

Participant 15 is a mother of a child with hearing impairment and a pediatrician. Her cousin oriented her to an NGO specialized in hearing impairment. She noticed the important role performed by this NGO in guiding the families to providers, to treatment needed, to financing agencies etc. She decided to create a hub in the pediatrician ward of the medical university where she works to guide the families of the patients through the system.

“He is my second child. I am a pediatrician, and my husband is a physician.

At birth, he had an extra 2 kilos of water, which is huge for a baby. He was born abroad, and we did a million-dollar workout, but we could not find the reason behind this case...

It was a surprise!

During early months, the baby was not growing up normally, he was fed via feeding tubes then he started to suck but a bottle would take up to hours, and these suffering parties. We were going from one physician to another. He was not interacting, we discovered that he has a hearing impairment. We started the battle of the hearing impair; we got the apparatus. We needed to tune it frequently. We started an intensive speech therapy treatment. When he reached school; we wanted inclusion, we refused to institutionalize him. We chose an inclusive school. He started to use a hearing assistive technology FM system in the classroom and continued with speech therapy sessions.

My cousin worked at an NGO specialized in hearing disabilities, she introduced me to the responsible of that NGO. They helped me a lot with my son's case. For example, they advised me to start a psychomotor treatment because people with hearing impairment would lose some sensors. I volunteered with them as a pediatrician.

Before having my child, and despite being a pediatrician, I was not aware of lot if information related to raising children with disabilities. Now I have professional and motherhood experiences. I experienced raising a child with hearing impairment, I know where to find needed stuff, who are the NGOs working in field and so... I would not be relying only on "the book; there is no clear map. You cannot learn it; you have to live it. Therefore, my colleagues (pediatricians) refer children with hearing impairment to me, a child with cardiac abnormality is referred to a pediatrician working on these cases we know each other experiences.

As a group of pediatricians who happened to be parents of children with disabilities. We created an informal orientation desk for families of children with disabilities. The executive secretary volunteered to compile information related to therapy centers, medical devices centers, NGOs working on disabilities. Whenever a patient needs anything, she volunteers and helps, provides contact, calls, coordinates.... where to find needed stuff, who are the NGOs working in that field and so...But all this is not a formal process.... But this is not a formal process it is a volunteer work because we are sensibilized to the cases of disabilities."

Table 14 below summarizes the main 2 event of the experience of participant 15

Table 14: Summary of main events of the experience of participant 15

Main Events	Description
1	<i>It was a surprise!</i>
2	<i>...these suffering parties. We started the battle of the hearing impair</i>
3	<i>We were going from one physician to another</i>
4	<i>Before having my child, and despite being a pediatrician, I was not aware of lot if information related to raising children with disabilities</i>
5	<i>I know where to find needed stuff, who are the NGOs working in field and so</i>
6	<i>As a group of pediatricians who happened to be parents of children with disabilities. We created an informal orientation desk for families of children with disabilities</i>
7	<i>The executive secretary volunteered to compile information related to therapy centers, medical devices centers, NGOs working on disabilities</i>
8	<i>Whenever a patient needs anything, she volunteers and helps, provides contact, calls, coordinates.... where to find needed stuff, who are the NGOs working in that field and so</i>

Source: Prepared by the author

4.2.4. A tailor-made treatment plan for children with Down Syndrome

Participant 16 is a mother of a child with Down syndrome. She has been traumatized by the disclosure of the disability of her daughter. She refused to follow the regular treatment care path available in Lebanon i.e., multiple therapists in geographically dispersed locations. Knowing of a home-based treatment developed by a group of therapists abroad, she travelled and started to become the informal caregiver of her daughter. She found this experience less challenging than coordinating between different therapists because she knew what she had to do and what to expect. Therefore, she decided to work with a group of physicians to develop a treatment care path for families with children with Down syndrome. The narrative below follows a chronological order.

“I used to work but when my daughter was born, I stopped working... we, a group of families having children with down syndrome, created an NGO specialized for Down Syndrome...I started to volunteer there. I am not a professional in that field; I was working on fund raising. When you get a kid with a case in Lebanon, you need to know what to do, where to go, of course you have the mouth to ear information and your network; but it is not enough.

When I knew (that her daughter has Down Syndrome) I started to read and ask. Then, we discovered that she also had heart disease. You know what! As if I died for the second time, you die first when they announce the problem, and you feel that you die again with each new complication. I screamed and said OK she is trismic and we need to learn how to live with her, but now we have to wait and maybe she will live maybe not!

Later she needed therapy. I was not convinced to go from one place to another and do the coordination (between the therapists). One of my friends, living abroad, told me about an early intervention program. I travelled and met a multi-disciplinary team who provided me with a home-based program that I implemented at home. Then, I met with the professionals every six months to assess her progress. Now when I look at this program it is basic , all people do the same for their children , nothing exceptional but they (multi-disciplinary team members) support you , they guide you and say do 1,2,3 you don't have to look around , do speech therapy, psychomotor and etc...they give a full program , you don't need a professional ,.....They tell you what to do and you do it. I could not understand that here in Lebanon I need to go here and there and drive from one place to another and no one is ready to coordinate, you need to pay a fortune so that they tell you if this is working or not. I decided not to get the help of a professional and I followed up the program by myself at home. When I used to meet the group, all the professionals met with her and wrapped it up and gave me feedback.

In Lebanon you are not helped at all unless you pay a fortune to be able to find someone that gives you an information. It is catastrophic, I suffer I cannot tell you how much even.... You need to beg the physician to tell, tell me what to expect ... Nobody supports you before supporting the child, you need somebody to guide you. I feel it is all about money, money...When she was born, it was completely lost.

That is why we decided to create the NGO to help other families having the same case since we already had some information and experience.). Group therapy helped because when we meet people facing the same difficulties, we could share experiences, you help yourselves and others, it is easier.

On the other hand, I had the idea of creating a checklist (a treatment plan for children with down syndrome) in collaboration with a university hospital. This list would be distributed to families who have children with disabilities. It is easier when you know what you have to do and when to do it!”

Table 15 below summarizes the main events of the experience of participant 16.

Table 15: Summary of main events of the experience of participant 16

Main Events	Description
1	<i>You die first when they announce the problem, and you feel that you die again with each new complication</i>
2	<i>(You) need to beg the physician to tell, tell me what to expect Nobody supports you before supporting the child</i>
3	<i>I started to read and ask</i>
4	<i>(I) met a multi-disciplinary team who provided me with a home-based program that I implemented at home</i>
5	<i>I had the idea of creating a checklist</i>
6	<i>(the plan was done) in collaboration with a university hospital</i>

Source: Prepared by the author

Drawing inspiration from Dutton's et al. (2014) framework of touchstones events , we aim at understanding the process by which innovative solutions emerged.

The analysis of our data shows a parallelism with the above-mentioned framework since it reveals explicitly or implicitly common touchstone events in the experience of the parents of children with disabilities : 1- shock by the disclosure of the disabilities of their children, 2- pain and suffering due to the inequity and lack of compassion of the healthcare system, 3- reliance on the healthcare professionals for all healthcare decisions , 4- dissatisfaction with the quality of care, 5- learning and accumulation of knowledge from diverse resources., 6- identification of gaps and needed services in the healthcare system, 7- emergence of combined new roles: patient expert and case manager.

Table 16: Common touchstone events.

Touchstone Event #	Description
1	Shock
2	Pain and suffering
3	Reliance on the physicians.
4	Dissatisfaction with the quality of care.
5	Learning and accumulation of knowledge
6	Identification of gaps and needed services in the healthcare system.
7	Emergence of combined new roles

Source: Prepared by the author

Our data also shows that when faced with dissatisfaction, the parents of children with disabilities reacted in two potential ways. They either respond to the dissatisfaction by the new emergent roles, or they go beyond being a patient expert and a case manager to becoming drivers of change, through collective solutions, in the community.

A closer look at our empirical data reveals common touchstone events in the process of creation of collective solutions. The parents identified: 1-needs such as the absence of a treatment protocol for children with Down Syndrome, 2-models such as a school abroad, 3-ideas of an organizational solution, 4-benefits from their previous knowledge, 5-receptive host organization, 6-resources for implementation.

Table 17 :Creation of collective solutions common touchstone events

Touchstone Event	Description
1	Identification of needs
2	Identification of a model
3	Ideas of organizational solution
4	Benefits from their previous knowledge
5	Receptive host organization,
6	Resources for implementation

Source: Prepared by the author

Looking more in-depth at the profiles of our participants showed certain similarities as presented in table 18 below. We noticed that all four participants have an advanced university degree, high absorptive capacity of knowledge and that they are used to operating autonomously. The advanced education and professional statues of these participants helped them to acquire knowledge and to transform it into organizational solutions (Ziam, 2010b)

Table 18: Profiles of participants who created organizational solutions.

Participant	Educational level	Professional Status
2	PhD-Health Sector-Hospital University	University Professor
10	Pharmacists	Pharmacist at her privately owned pharmacy
15	Health Sector- Physician	Pediatrician
16	Health Sector- Optician	Private clinic owner

Source: Prepared by the author

Summary of chapter 4

With the analysis of the individual solutions and the collective organizational success stories, we were able to identify the keystone events in the experiences of the participants. We also identified the emerged combined roles played to overcome the challenges of the highly fragmented healthcare Lebanese healthcare system.

In the following chapter, we will be addressing through an abductive approach the process used by parents to move from a traumatized individual to an organizational emotional broker.

Chapter 5- The metamorphose cycle: from a traumatized individual to an organizational emotion broker

This chapter answers our research question on What is the process followed by parents of children with disabilities to become resilient and how do the parents of children with disabilities manage to find solutions to the challenges they experience?

It is divided into 5 sections. Section 5.1. explains the process by which the disclosure of disability, a traumatic event, in an inequitable and non-compassionate environment leads the parent to a grief cycle. Section 5.2. explains how the parents pass the grief cycle to become resilient. Section 5.3. explains how the parents acquire and absorb knowledge and become a resilient knowledge broker. Section 5.4. explain how the parents are capable of triggering compassion in an organization operating inside a non-compassionate system. Thus, the parents become organizational compassionate brokers. Section 5.5. explains how the parents contributed to transforming negative emotions into positive emotion and eventually become organizational emotional brokers.

5.1 Disclosure of disability: the traumatic news

This section is divided into two subsections. Subsection 5.1.1. analyzes how the parents experienced the disclosure of the disability of their child. Subsection 5.1.2. analyzes the grief cycle lived by the participants after the disclosure of the disability.

5.1.1 The day of the disclosure: the unforgettable day.

The disclosure of the disability is a devastating event to the family. It is an “*unforgettable day*” (participant 9). It is a “*catastrophe*” (participant 16). It is the day when “*the time stopped*” (participant 3); “*in short it is the D-Day, the day when all hell broke loose*” (participant 21).

Having a child with disability means the destruction of the parents dream of having the child expected (Sen & Yurtsever, 2007). Walsh (2021) describes the birth of a child with disabilities as a critical event with unexpected complications. When the parents know about the disability of their children , their expectations are turned upside down (Sen & Yurtsever, 2007).

“It was a turning point in my life. I was too excited to have my first baby, expecting a child was a source of happiness and joy. I had not imagined that he might be sick or with disabilities”. (Participant 1)

It is a devastating event as one participant stated that she felt “*in a funeral instead of being happy for having a newborn child*” (participant 11). The adversity of this disclosure is not less traumatizing than the death of a beloved person (Walsh, 2021). Grief follows the loss of the beloved ones, and the parents grieve for the loss of their dream which is having a healthy child. Kübler-Ross & Kessler (2005, p. 7) identify five stages of grief, they are denial, anger, bargaining, depression and finally acceptance of the fact. The grief process is not linear, the stages are not in order. People might not pass through all the stages; these aspects could happen at different times of the cycle. Individuals do not experience grief in similar ways. “Grief is as individual as our lives” (Kübler-Ross & Kessler, 2005, p. 7). The participants grieved in different ways before they accepted that the child is disabled, a fact that they cannot change.

Kübler-Ross & Kessler (2005) stages of grief are denial, anger, bargaining, depression, and acceptance. Acceptance is the beginning of the healing process, it is when the individual start to move and evolve (Kübler-Ross & Kessler, 2009).

5.1.2. The grief cycles

Parents grieve for the psychological loss of a healthy child and sometimes they attribute blame to themselves or to each other's (Palazzi et al., 2015). This grief recurs each and every time the child condition changes (Palazzi et al., 2015). One parent said that she died for the second time when she discovered that her daughter needed an additional operation (participant 16).

This subsection analyzes our empirical data in the light of Kübler-Ross & Kessler (2005) stages of grief, before proceeding to the next section that analyzes how the participants reorganized their lives and became resilient.

5.1.2.1. Denial: Escape!

The parents are “*shocked*” (participant 21) and even traumatized. A participant stated that he traveled abroad for few days because he “*wanted to escape*” (participant 14). The word “*escape*” has a double interpretation. The first one is the physical escape which is traveling abroad and the second one is that he wants to deny having a child with disability. The shock is massive to the extent that some reactions were threatening. For example, one mother left her daughter and went running down the streets. She had an illusion that her daughter would not survive. She denied that fact that she would have to live with a child with disability.

“It was a catastrophe.... I left my daughter at the hospital and went running and screaming down the streets. Then, I went back to the hospital, I took her as a crazy,

called my sister-in-law and went to the church. I wanted to baptize her, the priest asked me why this urgency and I said because she is going to die!!!” (Participant 16).

The first communication of a diagnosis of disability in a child is an experience never forgotten by the parents (Hasnat & Graves, 2000). They remember the details of the moment when they were informed about the disability of their child (Hedderly et al., 2003). It is an “*unforgettable day*” (participant 11).

5.1.2.2. Anger: Why me!

The shocking news triggered anger. They might become angry at themselves and start asking “*Why me?!*” (Participant 6).

A mother said that she is the only one who has a son with such a severe case.

“I don’t know why, nobody knows why...why I am the only one who a full package (multiple disabilities)” (Participant 3).

Being the only one who has a child with multiple disabilities implies that she is asking “*why me?*”.

Individuals might also orient their anger at the providers. Some yelled at the physician informing them about the disability of their child.

“At sunset, the pediatrician came into my room in the hospital ...I was alone... He asked to see my family, I asked him to tell me! I am the mother! At first, he hesitated...I insisted, so he told me that there is something abnormal with my daughter...I replied in a very

loud and aggressive tone: “Abnormal !!!what is abnormal!! I was yelling at him”
(Participant 7).

One mother felt angry and blamed the physicians for “*leaving her alone*” without support.

“Nobody told me that “You” might have delay in walking, maybe mentally, maybe in comportment, maybe in speech ...They gave us this baby and they (the providers) have all withdrawn” (Participant 3).

This anger is a hidden pain. The agony amplifies when the person feels deserted and abandoned (Kübler-Ross & Kessler, 2009). This is the case of the parents who feel the inequity of the healthcare system and its lack of compassion. One mother was angry of the system for not helping her.

“I felt I needed help; the parents should be cared for in order to be able to take care of their child.” (Participant 27).

The pain is obvious, but the healthcare system does not respond to the yelling of the parents. Thus, the anger and agony intensify.

5.1.2.3 Bargaining: Do whatever it needs

Before the death of a beloved one, people bargain on what they could do so that their loved ones could be spared. After death, people bargain on what they could have done differently. Parents with children with disabilities bargain that they would “*do whatever is needed to live as everyone else (families who have children without disabilities)*” (Participant 14).

“I thought that if I follow up the instructions and he is given his medicines on time, he should turn out to be normal. I dedicated myself. During eight months, I prisoned myself with him at home, I was living in pajamas.” (Participant 27).

Another form of bargaining is searching for someone who can bring life to what it is used to be before the death. In our case, participants searched for providers who might be able to turn the situation to what they expected which is having a healthy baby.

“Whenever we knew about a specialist, we used to make an appointment and took him (her son) for consultation and for new opinion” (Participant 2).

“... whoever told us of a physician we consulted him.” (Participant 22)

Later, the parents “discover” that this is an “*illusion, disability is not a temporary disease, it is a lifetime condition*” (participant 27). This is when depression starts (Kübler-Ross & Kessler, 2009).

5.1.2.4. Depression: Leave me alone

At the beginning there is the denial and the bargaining, depression starts when the individual realizes that his or her child is not going to heal. Some participants explicitly stated that they were “*depressed*” (participant 5, 24 and 28), while others mentioned the symptoms of depression without explicitly mentioning that they were depressed. For example, a mother spent hours crying.

“I did suffer at the beginning, I took me one year to realize (that disability is permanent), I used to sit alone for hours and cry in silence (because of her son disability)” (Participant 9).

Depression starts when the mind is oriented on the unfortunate reality of the present moment. (Kübler-Ross & Kessler, 2009).

Some participants withdrew from society and refuse to share their feelings with others. As one participant explained that at the beginning, she refused to share experience with other families who have similar cases, and she withdrew from social life.

“I want to be left alone. I don’t want to talk to anyone... I will take care of my daughter and let everyone takes care of his kids.” (Participant 16).

Boris Cyrulnik, a French neuropsychiatrist studying traumatic memory, considers that silence forces the traumatized person onto “the treadmill of depression” (Cyrulnik, 2019). Though according to Kübler-Ross and Kessler (2009) depression is a normal stage of grief which is a process of healing. The grief cycle ends when the individual accepts his or her new norm, living without the beloved one.

5.1.2.5. Acceptance: Recreate oneself

Acceptance stage starts when we recognize that we “*can never replace what has been lost , but we can make new connections, new meaningful relationship*”(Kübler-Ross & Kessler, 2009). It is the stage of grief when the person starts to grow and to evolve. At this stage, the individual starts to adjust and adapt his or her new circumstances, to reorganize the roles and to assign some roles to him or herself (Kübler-Ross & Kessler, 2009).

The parents redefined their roles. Some became medical caregivers for their children for example one mother “*used to do the intubation*” despite her “*fear and anxiety*” because her son could not suck and has to be fed via tubes (*participant 27*).

Parenting a normal child is stressful; parenting a child with disability brings life changing effects (Cauda-Laufer, 2017). The coming of a child with disability causes a myriad of challenges to parents (Walsh, 2002) for which they are not prepared. Parents are not even trained to care for a healthy child. They *“do not know how to do the basic stuff as feeding a baby or changing diapers”* (Participant 5). They find themselves providing medical services such as feeding a newborn via tubes.

With time, the participants *“accept and adapt”*. They start a new lifestyle; they make new relationships.

“Life changes us a lot like a cabbage, layers and layers that will disconnect you from yourself. You find yourself detached, from what you used to be. You have new friends, new relationships” (Participant 23).

Sometimes they even laugh at the way they behaved at the beginning.

“I start explaining and talking about down syndrome, I feel released, it doesn’t bother me. But you need a period to accept and adapt...Now whenever I look at her baptism certificate (stating risk of death); I laugh...” (Participant 16).

One mother summarized her experience saying:

“This is challenging. While you feel that you are going to collapse, you will take it as a turning point, and you recreate yourself.” (Participant 6).

When the individual accepts the reality, the healing process starts (Kübler-Ross & Kessler, 2009). The person starts to express and share hard experiences, he or she start to “process” the trauma and develop resilience (Cyrulnik, 2019).

5.2. Becoming resilient: using resources to get stronger

In our previous section, we have shown the cycle experienced by the parents following the traumatic event of the disclosure of the disability of their child. We have also shown how the parents develop a healing process which starts with acceptance of reality. Once the individual accepts the reality and start to share traumatizing experiences, the resilience process begins (Cyrulnik, 2019; Kübler-Ross & Kessler, 2009) .Therefore, the resilience process seems to take roots into the traumatic event of the disability.

This section is divided into two subsections. Subsection 5.2.1. provides a general idea on the concept of resilience. Subsection 5.2.2. presents Walsh's (2003) resilience framework and analyze the empirical data in the light of this framework.

5.2.1. Family resilience in overcoming traumatic events

Cyrulnik highlights the difference between healing from a trauma and becoming resilient after a trauma.

“Resilience is not a case of returning to a previous state, because returning to a previous state is healing, whereas resilience is a matter of getting back on the right track, although you can’t refer to it as “normal” development, because you never forget the trauma. However, you are no longer a slave to your memories because you’ve managed to make something out of those experiences, and that’s the next chapter. Resilience is the resumption of a healthy developmental path after experiencing psychic agony or trauma.”(Cyrulnik, 2019)

Resilience is *“a complex construct and it may be defined differently in the context of individuals, families, organizations, societies, and cultures”* (Southwick et al., 2014).

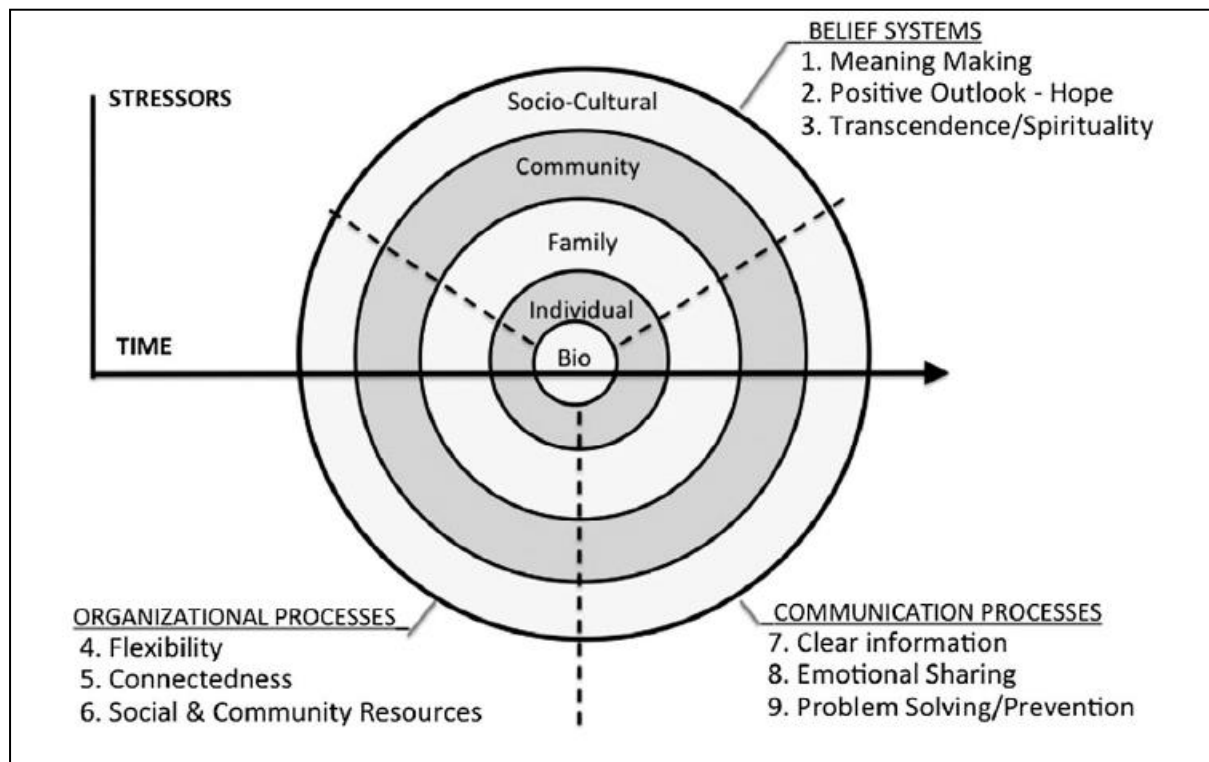
Our study is focused on how parents of children with disabilities faced the adversity of dealing with a child with disability. The whole family is impacted by the response of the parents towards stressors. Our abductive methodology brought us back to the literature, and thus we identified Walsh (2012) family resilience conceptual framework. This framework adopts a family systems’ perspective that identifies resources available for individual resilience through the family (Walsh, 2016b). It seeks to understand *“crucial variables contributing to individual resilience and well-functioning families”* (Walsh, 2003). This framework identifies multilevel key processes that *“reduce the risk of dysfunction, buffer stress, and encourage healing and growth from crisis”* (Walsh, 2003).

We believe Walsh's (2003) family resilience framework is well adapted to our research topic because it is useful in understanding families when facing an adverse event. Our research shows that the participants used different processes similar to those identified by Walsh's framework allowed us to consider them as resilient.

We therefore used this framework to understand how the parents transformed a traumatic event into a successful collective solution.

Walsh's (2021) family resilience framework proposes dynamic processes that can be mobilized by family members inside their family unit or while interacting within their environment (Walsh, 2021). Walsh (Walsh, 2002, 2003, 2016b, 2021) argues that those key transactional processes enable the family to rebound from highly stressful events, to buffer the effects of disturbances, to adapt positively and resourcefully to prolonged adversity such as having a family member with disability. These processes require the families to activate its resources and strengths when faced the challenges (Walsh, 2021). Based on extensive studies on family resilience, Walsh identifies nine key transactional processes divided into three domains or dimensions: the belief system, the organizational patterns, and the communication processes (Walsh, 2021).

Figure 13: Walsh (2016b) Multilevel recursive processes in resilience



Source: (Walsh, 2016b)

Each dimension encompassed three core transactional processes. These transactional processes are mutually interactive and synergistic, both within and across domains. For example, meaning-making facilitates communication clarity, emotional sharing, and problem-solving, and reciprocally, effective communication processes facilitate shared meaning-making. Our empirical data will be analyzed based on this framework in the part below.

5.2.2. Reading our empirical data through Walsh's map on family resilience

In the following, we will use Walsh' map , the family resilience framework, to assess the resilience processes deployed by the participants (Walsh, 2016a, p. 101). We will start with the

belief system, followed by the organizational patterns and we end up with the communication and collaborative problems solving processes.

5.2.2.1. Belief system: A message from God

Walsh describes the family belief system as “*the heart and soul of resilience*”, she used this phrase as the title of the third chapter of her book “Strengthening Family Resilience” (Walsh, 2016a, p. 39). Beliefs help family members to “*make- meaning*” of the adverse event, to have a positive outlook, and to give spiritual value and purpose (Walsh, 2002, 2003).

The family belief systems influence the way the family perceives the crisis, their suffering, and their available options. This dimension of resilience encompasses three core transactional processes: making meaning of the adversity, a positive outlook and transcendence and spirituality.

Making – meaning

The resilience of the family is related to its ability of “making-meaning” of the adversity. Walsh argues that “making-meaning” of the adversity is related to the ability of the family to view it as a shared challenge, to normalize and contextualize it, and to give it a sense of coherence (Walsh, 2003).

According to Walsh (2003), a shared challenge means “*together we are stronger*”. Normalization and contextualization of the challenges is achieved when the individuals view the dilemmas as common and expectable among families in similar context. The sense of coherence is a belief that the crisis is “comprehensible, meaningful to tackle , and

manageable”(Walsh, 2016a, p. 9) and it involve efforts to understand the problem and to identify available resources.

The family members supported each other the *“mother and mother-in-law come to take care of the child (son) so the mother (I) can get some sleep”* (participant 6).

The participants did not consider the disability of their children as a *“taboo”* (participant 25) on the contrary they *“accepted them as they are”* (participant 11). They view the daily challenges as normal in such a context.

“He (son) wakes up at 3 AM, he is hyperactive, so I have to sit by his side so that he won’t hurt himself. it is normal in his case. He might fall asleep at 6:00AM, but I cannot go back to bed because I have to get my elder son ready for school. Then, I have to prepare him a special breakbeat because he is allergic to many substances...I have quitted my job to take care of him ...it is normal in families having children with disabilities. I like to focus on the positive sides...he is happy, he enjoys his food ...” (participant 23).

The participants framed the situation as manageable; they accepted that some issues are controllable while others are not. As one participant stated:

“It is not necessary that everything that does not meet our expectations is bad or wrong” (participant 6).

The parents identified the challenge which is the disability of their children and tried to provide the best healthcare services given their available resources.

As one mother said:

“Based on what is available, we tried to maximize our benefits” (participant 5).

A successful “meaning- making” process provides a positive outlook allowing the families to consider the crisis as an understandable and manageable situation (Greeff & Nolting, 2013).

Positive outlook

Positive outlook encompasses hope, active initiative, and perseverance.

Hope means that the future could be better regardless of the chaos and suffering of the past. According to Panter- Brick if she has *“to boil down resilience to one word it would be hope”*. She cited Eggerman and Panter-Brick explaining that *“hope is not the conviction that something is going to turn up well, but the certainty that something makes sense”* (Southwick et al., 2014).

The participants did not deny the *“limitations of their children” (participant 6)*, but they *“believed”* that they have capabilities and worked *“to include them in the normal family’s social life, to join family gathering and ceremonies” (participant 14)*.

Active initiative and perseverance are promoted by a “can-do-spirit” a belief that makes individuals do their best and become active participants in a “tenacious search for solution”(Walsh, 2016a, p. 105).

As one mother explained:

“I wanted everyone to say God Bless her (daughter)!!.... I started to work on her development, speech therapy, early intervention. at home, I got educational and developmental toys.” (Participant 11).

Walsh’s (2003) key processes interact across and inside the domains of the resilience framework (Walsh, 2021). In this sense, hope and “can do spirit” foster perseverance and enhance the family resilience (Gunnestad, 2006; Walsh, 2021).

Transcendence and spirituality

Another process fostering family resilience is religious and spiritual beliefs. Spiritual beliefs help families in finding “*strength, comfort and guidance in adversity*” Walsh (2003).

This process is widely used by the participants for example two mothers interpret a dream they had during their pregnancies as “*a message from God*” (participants 6 & 9). One mother narrated a dream she had while laughing. She dreamt that she was saved from the doomsday suffering because she took care of her son with disability “*so whatever he does even when he behaves in a difficult manner, I remember that dream, I laugh and say to myself...I will be rewarded*” (participant 6).

Another participant said that his son is a “*blessing*”, (participant 14), while a mother stated that her daughter “*is a gift from God*” (participant 7).

Religious beliefs and optimistic outlook interact together to give a feeling that this struggle to adapt would be worthy in the future (Greeff & Nolting, 2013).

5.2.2.2. Organizational processes: I lived in my car

The second level of Walsh's multilevel recursive processes in resilience is the organizational patterns mainly being flexible, having family connectedness or cohesion, and mobilizing social and economic resources (Walsh, 2016a, p. 103).

Flexibility

Flexibility is being "open to change"(Walsh, 2003), it is a core process in the resilience framework.

When families encounter challenges such as disability, they cannot return back to their original stage before the disclosure of the disability of the child. Resilience is more than "bouncing back", it involves adaptive change to fit new challenges. Families have to adapt to the new condition, they need a structural reorganization (Walsh, 2003).

Our empirical data revealed that participants changed their daily lives routines to provide care for their children. For example, a mother "*quitted her job... lived in the car; I (she) spent all the afternoon going from one therapist to another*" (participant 28). Another mother "*quitted her job and became the therapist*" (participant 16). A participant changed her career as one mother who "*studied and became a certified therapist*" (participant 19).

Connectedness

Connectedness is the emotional and structural connection among family members. It encompass mutual support, collaboration, and commitment of the family members (Walsh, 2016a, p. 73)

The participants supported each other; they were like team members. For example, some parents “*quitted (their jobs), because I (they) had to go from one therapist to another, so it became difficult, and I cannot.*” (Participant 28) and “*agreed that you (the mother) will give him the emotional support, you follow up the treatment and I (the father) will take care of the financial support*” (Participant 6).

Being obliged to quit a career is disappointing and becoming the sole bread winner is stressful as well. Nonetheless, the parents accepted these changes for the sake of the family and the child with disability.

Moreover, the child treatment in a highly fragmented system such as the Lebanese healthcare system needs to commute between different clinics, to go approval of multiple financing agencies. This task needs full commitment. A father described the follow up of his son’s treatment as his “*full-time job*” (participant 14).

The parents make a team whose members support each other to reach their goals: providing healthcare for their child with disability.

Mobilize social and economic resources

Walsh’s (2003) framework identifies the process of mobilizing social and economic resources as of a great importance. A major key process to parents of children with disabilities is mobilizing social and economic resources.

Being able to ask for support from close or distance relatives, from neighbors and from colleagues help families to respond successfully to crisis (Nadrowska et al., 2022; Walsh, 2003). The participants were helped in their daily life activities. For example, a participant

stated that she asked her mom *“to take care of my eldest son because (at that moment of time) my youngest son needs me more...” (Participant 28).*

A participant was thankful to her neighbors.

“They used to cook for us, to clean our house and to wash our clothes because they saw how tired we were due to lack of sleep and rest” (participant 3).

The social network of the families, and their willingness to ask for help improved their resilience. The emotional support played a major role as a participant explained:

“To tell the truth, my family and my in-laws supported us too much. They all loved her. My surroundings, family, and friends supported me so much and this is very important” (participant 11).

The social network (personal and professional) also provided information to the participants. For example, participant 24, who is a schoolteacher, benefited from her professional network to locate inclusive schools. Participant 1 personal network helped them to find orthopedics.

“We relied on our personal and family network. Several doctors were among our family members: Thus, we decided to ask them for guidance and opinion. They suggested a list of orthopedics”. (Participant 1)

In addition to social capital, financial security is vital to resilience, as caring for a child with disability *“needs a fortune”*. One participant stated

“The school fees were 10,000\$ for the integration program (class, assistance, 2 sessions psychomotor, 2 sessions speech therapy), we needed to pay additional 200\$

per month over 9 months for an assistant to our child...the psychologist charged 50\$ per session twice a week in summer and once a week in winter....an afternoon program costed another 1000\$ per month” (Participant 10).

Social and economic resources are dynamic interactive processes used by resilient parents to tap into their networks for concrete support. Resilient parents mobilize their network to acquire information, to find providers and sometimes to finance services. For example, one mother participated in a TV documentary on the difficulties encountered in schools by families of children with disabilities. During the interview, she highlighted that she *“as a parent, I (she) could not afford an assistive device that would help my (her) son to stand up few hours during the day. A member of the audience introduced me (her) to an NGO that provides these devices at an affordable rate” (Participant 4).*

5.2.2.3. Communication processes: talking is my cure

The last domain of Walsh’s (2016a, p. 103) resilience framework is communication and collaborative problem solving processes. These processes consist of clarity of communication, open emotional sharing and collaborative problem-solving.

Clarity of communication

Direct, clear, and honest communication helps family members to understand the situation and facilitate taking decisions. One mother stated her husband was assigned to inform her about the disability of their child. *“He was anxious and stressed trying to hide the news”*. Thus, she *“decided to tell him clearly”* that she already knew about the disability of their newborn child. This conversation *“relieved his pain.” (Participant 6).*

Open emotional sharing

The ability to express personal feelings, both positive and negative, is crucial to resilience.

The climate of trust and confidence fosters this ability. Resilient family members feel confident to share their negative feeling

“Talking about it (her concern) made feel relaxed and tranquil.” (Participant 6)

“I feel that my therapy is to talk about it (feelings, challenges)”(Participant 16)

They also share feelings of love and gratitude. They appreciate the roles of each other. One mother stated that her husband is a very caring person.

“I know he is worried about me, and I know that how much he loves me”. (Participant 11).

Collaborative problem-solving

This process is a creative brainstorming for reaching solution as a family. This involves negotiation, an exchange of ideas and common concrete goals (Walsh, 2002). The parents exchange thoughts and then take the appropriate decision.

“We discuss the issue together and define what is ideal for our child” (Participant 5).

A good example of this process is the decision reassigning the roles of the parents, one parent would follow the healthcare treatment and the second will ensure the economic cost. The parents defined their objective: providing healthcare for their children with disabilities. They find that the system is highly fragmented. Someone has to accompany the child, drive from one clinic to another and to ensure the financing agent approval. This is a *“full time job”*. The

healthcare services costs “*a fortune*”. Therefore, one of them has to follow the treatment and the second one has to earn income. They decided that the breadwinner would be the parent who earns a higher income. Thus, the second parent quitted his or her job and followed up the healthcare treatment.

Our analysis has brought out that parents have passed through the grief cycle till they accepted the disability of their children. They gained new roles to response to the crisis as becoming informal healthcare providers for their children according to this new reality. Through the analysis of the process by which parents became resilient, we showed that our participants comply with Walsh’s Family Resilience Framework (Walsh, 2003, 2021). Thus, they are resilient as per Walsh’s framework. They built on their belief systems and their “can-do-spirit” to develop their organizational patterns and communication and problem-solving processes.

As Walsh (2003) stated “*the paradox of resilience is that the worst of times can also bring out our best. A crisis can yield learning, transformation, and growth in unforeseen directions.*”

We have illustrated in the table below the most expressive verbatim that apply to each domain and key process.

Table 19 below summarizes the participants’ most expressive verbatim grouped according to the domains identified by Walsh’s (2003) framework.

Table 19: Most expressive verbatim per each domain and key process.

Domain	Key Processes	Representative Verbatims
Belief System		
	1-Making-meaning	<i>"It is normal in families having children with disabilities. I like to focus on the positive sides...he is happy, he enjoys his food ..."</i> (participant 23).
	2-Positive Outlook	<i>"I wanted everyone to say God Bless her (daughter)!.... I started to work on her development, speech therapy, early intervention. At home, I got educational and developmental toys."</i> (Participant 11).
	3-Transcendence and spirituality	<i>The child "is a gift from God"</i> (participant 7).
Organizational patterns		
	4-Flexibility	<i>A mother "quitted her job... lived in the car; I (she) spent all the afternoon going from one therapist to another"</i> (participant 28).
	5-Connectedness	<i>"You will give him the emotional support; you follow up the treatment and I will take care of the financial support".</i> (Participant 6).
	6-Mobilize social and economic resources	<i>"To say the truth, my family and my in-laws supported us too much. They all loved her. My surrounding, family, and friends supported me so much and this is very important"</i> (participant 11). <i>"As a parent, I (she) could not afford an assistive device that would help my (her) son to stand up few hours during the day. A member of the audience introduced me (her) to an NGO that provides these devices at an affordable rate"</i> (Participant 4).
Communication processes		
	7-Clarity of communication	<i>The mother "decided to tell him (her husband) clearly" that she already knew about the disability of their newborn child. This conversation "relieved his pain."</i> (Participant 6).
	8-Open emotional sharing	<i>"I feel that my therapy is to talk about it (feelings, challenges)"</i> (Participant 16)
	9-Collaborative problem-solving	<i>"We discuss the issue together and define what is ideal for our child"</i> (Participant 5).

Source: Prepared by the author

5.3. Parenting a child with disability: a life-changing experience

In this section, we analyze how the parents developed their projects in the light of the absorptive capacity (ACAP) theory which is the “bedrock” of theories of innovation (Zou et al., 2018); we referred to ACAP theory to understand the process used by these participants to create their innovative projects and to analyze the knowledge brokering role played by these participants.

Our results concur with studies showing that parenting a child with disability is a life-changing experiences or transformational experiences (Bayat, 2007; Scorgie et al., 2004). During the analysis of our empirical data the experiences of four participants seized our attention. These participants played an additional role, in addition to being a parent and an informal caregiver, as all other participants, they became informal knowledge brokers. Knowledge broker is defined as:

“Knowledge brokers are those individuals or organizations that profit by transferring ideas from where they are known to where they represent innovative new possibilities. They transfer these ideas in the form of new products or new processes to industries that has little or no previous knowledge of them.”(A. B. Hargadon, 1998)

They seized innovative projects ‘broker ideas. They identified resources needed for their projects inside organizations. Later they approached these organizations to execute their projects. They triggered compassion and they succeeded in convincing the organization’s representative to implement their plans.

This section is divided into three subsections. Subsection 5.3.1. presents, from the analysis of our empirics, the role played by the participants. Subsection 5.3.2. present Cohen and Levinthal (1990) model and an analysis of the processes used by the participants in the light of this model.

5.3.1. Endorsement of the informal knowledge brokering role

This subsection aims to present why we argue that these four participants became informal knowledge brokers.

The analysis of our empirical data revealed that four parents were able to identify their needs, acquire resources to build bridges between themselves and the healthcare system. Those bridges filled the gaps between the needs of the patients and the services provided by the system. They established solutions for their needs inside well-established organizations. We will refer to these solutions by organizational solutions. Table 20 below lists the four organizational solutions, projects, developed by the four participants.

Table 20: Organizational solutions created by the four participants.

Case	Project name
2	Creation of socio-medical center inside a school.
2	Creation of an inclusive university program.
10	Creation of an inclusive socio-medical center for Autistic Children inside a regular school.
15	Creation of disability hub inside the pediatric ward of a medical university
16	Creation of an NGO working on treatment protocols.

Source: Prepared by the author

The creation and implementation of the organizational solutions stimulated a deeper analysis of the participants' experiences. This analysis revealed that the four participants identified

knowledge, absorbed it, and created innovative solutions. This role concurs with the role of a knowledge broker.

The concept of knowledge broker dates to the late 1800s. It emerged in the Germanic countries to help create informal network to connect the industry with the universities (Lomas, 2007). The research on knowledge broker is well developed on individuals who work at the frontiers of organizations such as researchers, policy maker, managers and practitioners (Haas, 2015; Lomas, 2007; Meyer, 2010). Despite these extensive studies on knowledge broker concept or connection officer, agents of change , gatekeeper (Cohen & Levinthal, 1990; Haas, 2015; A. Hargadon, 2002; Meyer, 2010; Schweisfurth & Raasch, 2018; Zahra & George, 2002; Ziam, 2010a) , these researches studied knowledge brokering performed by employees or actors at the frontier of the organization. Some researchers have worked on the patient as innovator in term of inventing a device or platform (Demonaco et al., 2020). Other studied the role of the client as a source of knowledge (Storey & Larbig, 2017). However, we did not identify studies on how a user of a system or service, the parent in this case, could become an informal knowledge broker and create an organizational solution. We used the term “informal knowledge broker” to refer to the participant who created the organizational solution. We mean by the word *informal* that the person is not internally employed by the organization nor an external contractor. He or she is not required to broker knowledge through an official arrangement whether as employee or external consultant. The “informal” Knowledge broker acts out of choice as the “informal” caregiver (Goodhead & McDonald, 2007, p. 16). As the healthcare research refers to parents of children with disabilities as informal caregivers when they provide caregiving tasks such as companionship, nursing as personal care (Goodhead & McDonald, 2007; Larson, 2010; Lekholetova et al., 2020; Resch et al., 2010; Sawatzky &

Fowler-Kerry, 2003), we refer to “informal knowledge broker”.to parents who able to create innovative solutions though not contractually related to organizations.

5.3.2. The path to becoming informal knowledge brokering

The analysis of the results showed that all participants wore two processual hats: 1-the hat of the parent and 2- the hat of the case manager coordinating professional caregivers. A deeper analysis of the empirical data revealed that the four participants who created organizational solutions had a third hat that of the informal knowledge broker.

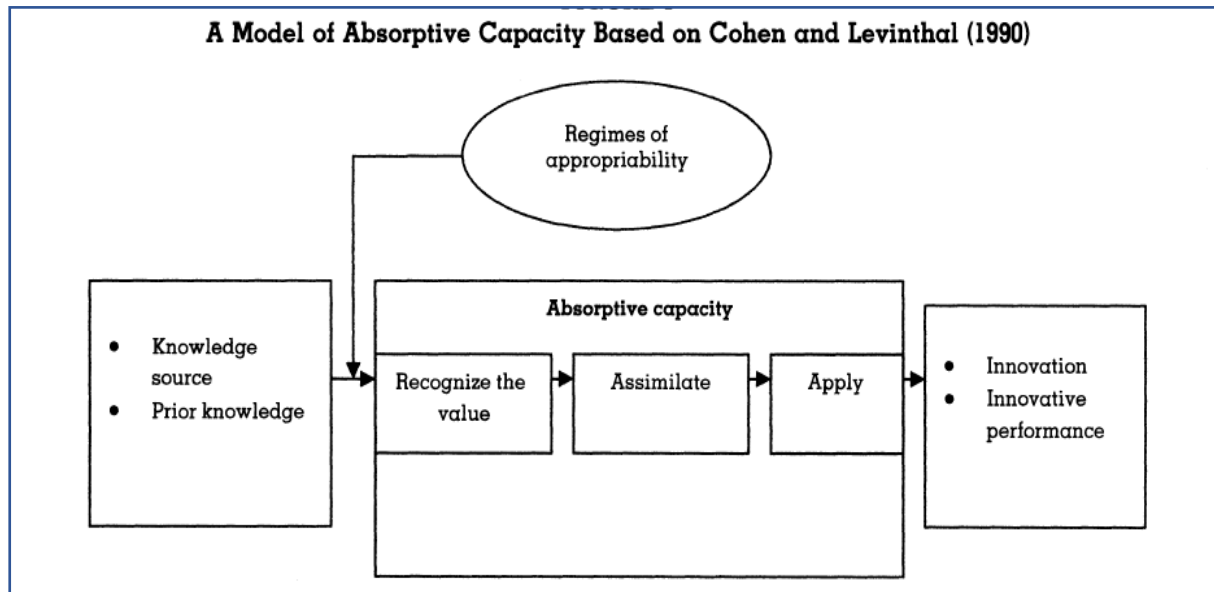
These participants followed similar paths. The path started by the identification of an unmet need. The participants benefited from a source of knowledge, they identified and mobilized resources, and generated an organizational solution. This process has been reactivated each time the participants identify a new unmet need. Participants had one additional hat, that of the informal knowledge broker.

This subsection presents first, the Cohen and Levinthal (1990) model. Then, it presents in a chronological order the path followed by the participants starting with the identification of an unmet need, the usage of their prior knowledge and the presence of a source of knowledge.

5.3.2.1. Cohen and Levinthal (1990) model of absorptive capacity

The participants, as informal knowledge brokers, succeeded to create “new services” inside the hosting organization. The capability of a firm to innovate is labelled by Cohen and Levinthal (1990) the absorptive capacity. The absorptive capacity is the ability of an organization to recognize the value of external knowledge, acquire it, assimilate it and apply it to commercial end (Cohen & Levinthal, 1990).

Figure 14: Cohen and Levinthal (1990) model



Source: (Todorova & Durisin, 2007)

Cohen and Levinthal (1990) propose a model of the absorptive capacity of organization that stresses on the importance of the role of the individual, who is an employee of the organization, in the process of knowledge absorbance (Cohen & Levinthal, 1990; Todorova & Durisin, 2007; Ziam, 2010a). Though the organization's absorptive capacity is not the sum of the absorptive capacity of its employees, it remains highly affected by the employees (Cohen & Levinthal, 1990).

In most of the studies, the knowledge broker is an employee of the organization (Cohen & Levinthal, 1990; Haas, 2015; A. Hargadon, 2002; A. B. Hargadon, 1998; Haryanti & Subriadi, 2022; Todorova & Durisin, 2007; Zahra & George, 2002; Ziam, 2010a; Zou et al., 2018). Some researchers focused on customer as a knowledge source (Alejandra Flechas Chaparro et al., 2021; Storey & Larbig, 2017).

The literature lacks studies on outsider who is a knowledge broker, and our literature review shows that there is no model explaining how an outsider, the parent in our study, can stimulate innovation inside an organization. Therefore, we decided to get inspired by theory of Cohen and Levinthal (1990) whose seminal article introduced the concept of absorptive capacity. According to them, the absorptive capacity depends on prior knowledge, the availability of an external source of knowledge and it is conditioned by a regime of appropriability.

In the following section, we revisit our results in the light of the absorptive capacity model proposed by Cohen and Levinthal (1990). We will not study the components of the absorptive capacity, mainly the value recognition, the assimilation and application of knowledge since they are related to the organization. The scope of our research would be limited to the factors affecting this capacity particularly the source of knowledge and the prior related knowledge. We will exclude the regime of appropriability from our scope since it is irrelevant to our context. The parents were not interested in protecting their acquired knowledge. On the contrary, they created solutions to solve their problems and *“to help other families having the same problem” (participant 16)*.

5.3.2.2. The informal knowledge broker absorptive capacity model

This subsection analyses our results in the light of Cohen and Levinthal (1990) model. We start with the unmet need as a trigger to the overall process, then we identify the role of prior related knowledge and the availability of the source of knowledge.

Unmet needs

The participants first identified their unmet needs. It is the problem that triggered the process of the creation of an organizational solution.

For example, participant 2 stated that:

“We had the idea of building a socio-medical center inside an inclusive school for two main reasons. Children with disabilities need sometimes extra therapy hours. Parents were obliged to search for therapists after school hour. They usually need to commute, and it is an extra burden, and they need to coordinate between the socio-medical providers present at the school and those in their private clinic. This center would contribute positively to the care. First, the child who needs extra therapy session can have them at his school building after his classes. Thus, the burden of transportation is relieved. Secondly, he would have the same providers so the burden of coordinating the care disappears as well”.

This same participant initiated a vocational university program for children with disabilities. She explained that:

“When a child with disabilities could not pass his or her brevet tests, schools are obliged to dismiss them. In this case, the parents find themselves have to make one of two decisions: either to get the child back home or they have to admit them to special institutions. If the child is back home, he or she would forget all what he has learned. Facing this challenge, we decide to establish a vocational center inside a university campus so that children who have reached 17 or 18 years old could join a university and get trained to have a job that suits his capabilities.

Participant 10 did not find a school that accepted her autistic child. Participant 15, who is a pediatrician and a mother for a child with disability, noticed that parents of children with disabilities need guidance on the organizations and providers working on different types of disabilities.

Participant 16 wanted a *“checklist or a road map”* to know how to care for her daughter.

Those participants identified an unmet need, and they searched for knowledge to fill the gaps. The unmet need is the trigger that activated the process of creating an organizational solution. Table 21 below summarizes the actions taken by each participant to respond to his/ her unmet need. This response came as an innovative project was concretized by an organizational solution.

Table 21: Unmet needs and their corresponding organizational solutions

Participant	Unmet need	Project name
2	Lack of coordination and geographical scattering	Creation of socio-medical center inside a school.
2	Lack of inclusive vocational education for persons above 17 years old	Creation of an inclusive university program.
10	Lack of inclusive school admitting autistic students	Creation of an inclusive socio-medical center for Autistic Children inside a regular school.
15	Lack of orientation for parents with children with disability on where to find care providers	Creation of disability hub inside the pediatric yard of a medical university
16	Lack of a clear follow up plan for children with down syndrome	Creation of an NGO working on treatment protocols.

Source: Prepared by the author

Prior related knowledge

“The ability to evaluate and utilize outside knowledge is largely a function of the level of prior related knowledge.”(Cohen & Levinthal, 1990)

Researchers provide evidence that due to prior knowledge individuals are able to recognize relevant information and absorb it (Cohen & Levinthal, 1990; Todorova & Durisin, 2007; Ziam, 2010a). Prior knowledge includes education, basic skills, shared languages, and information about latest scientific and technological developments (Ziam, 2010a). The accumulation of prior knowledge increases the ability to acquire new knowledge or to put new knowledge into memory, and the ability to use it and apply it when needed. Thus, sometimes knowledge broker combines new ideas with old knowledge to respond to a need or to solve a problem (Ziam, 2010b).

Though the participants rarely mentioned this prior knowledge in an explicit manner, the idea of creating a vocational program inside a university might be a good example on the contribution of the prior knowledge of these participants to the creation of the organizational solution.

“(I am) familiar with university program that are flexible and not regulated by the ministry of education. These programs target seniors who are interesting in learning specific skills or information such as theater, history of art, cinema, photography, and others. I had the idea of creating a similar program customized to the needs and capabilities of children with disabilities” (Participant 2).

Participant 2 is a public-health expert working in a university medical campus. Her prior knowledge is diversified between two domains: the healthcare systems and the educational system. This position is an asset serving for accessing and mobilizing resources (Williams & Shepherd, 2018) needed for their brokerage role.

The educational and working place of these participants presented in table 22 show that all participants were healthcare professionals. Thus, they have the academic knowledge of healthcare acquired through their studies. They also have tacit knowledge of the healthcare system, which is acquired through practice. Moreover, the organization in which they work, facilitates their access to knowledge, resources, and networks.

Table 22: Educational and working place of the informal knowledge brokers.

Participant	Participant educational level	Working place
2	PhD-Health Sector-Hospital University	University medical campus
10	Pharmacists	Private Pharmacy
15	Health Sector- Physician	University medical campus
16	Health Sector	Private clinic

Source: Prepared by the author

Sources of knowledge

Instrumentally, compassion often involves the provision of resources (e.g., time, concern, material goods) that can help people resolve or cope with the sources of their suffering and recover the ability to carry on with their lives (Dutton et al., 2014)

These participants benefited from their prior knowledge, they had access to a model that served as a source of knowledge for example, the ABA therapy program abroad and the multi-disciplinary team and home-based therapy are forms of sources of knowledge. Their professional and social network played an important role in contributing to their knowledge. They had access to privileged networks that can give them access to system knowledge which is mostly related to having colleagues in senior positions who can facilitate the navigation of a specific system (Willis et al., 2016).

This subsection presents the models that inspired the participants in creating their organizational solutions before analyzing the role of network as source of knowledge.

A model as a source of knowledge

The presence of a source of knowledge is crucial to the process of brokering knowledge. The innovative ideas are often the recombination of existing ideas from a range of fields, or disciplines. Knowledge brokering is sometimes an inventive combination reached when the knowledge broker has access to wide range of industries (A. Hargadon, 2005; A. B. Hargadon, 1998). These fields and disciplines present large pools of knowledge that can be used by the knowledge broker (Ziam et al., 2009)

“Most innovations result from borrowing rather than invention” according to March and Simon (1958:188) cited by Cohen and Levinthal (1990).

Knowledge brokering in this context is about recombining existing elements such as processes, people, ideas. It is similar to Henry Ford innovation of “mass production” whereby he did not invent the automobile, he had developed a new manufacturing process (A. Hargadon, 2005) .

The parents had experienced care coordination. For example, participant 2 explained that

“When he (the son) started his treatment, the two therapists were at a university campus, in the same building thus it was easy. Then, at a certain age, I was obliged to get the treatment outside the university campus...it became difficult when we started to commute between the clinic and to coordinate between the providers.”

Participant 10 stated that she traveled abroad to seek healthcare for her son. She copied the treatment provided abroad and created a socio-medical inside a school.

“He (the son) started to attend a specialized class in a regular school in the morning. He had one to one therapy sessions, then group therapy sessions. We spent 9 months there following this schedule: school in the morning and afternoon ABA therapy....and I came back to Lebanon, because I could not leave my other kids...I searched here to see what I can do... I could not find a school like the one there, and I didn’t want to admit him into a specialized institution... When I failed to find one, I decided to create one.”

The informal knowledge brokers did not invent a new treatment. They developed new processes inside the organization. Schools are not socio-medical centers, the informal knowledge broker combined the service of education with that of healthcare. They looked at the need of the person in his wholeness. A disabled child is child and a disabled. He or she needs socio-medical services and at the same time he or she needs to be educated. Education and healthcare are basic needs. The “informal knowledge brokers” succeed in integrating those services in one organization for the good of the child with disability.

Participant 15 explained that one NGO specialized in hearing impairment contributed positively to her experience by sharing information on the providers, the devices, and therapies.

“I learned a lot from an NGO specialized in hearing impairment care. They orient you on where to find services and devices, and on the therapists needed....”.

While participant 16 declared

“I travelled and met a multi-disciplinary team who provided me with a home-based program that I implemented...we met every six months to assess her progress.... they guide you ...they tell you do 1,2,3.”

Those participants referred to an external model as a “*source of knowledge.*” Table 22 below summarizes these sources of knowledge and their corresponding unmet need and organizational solution. Participant 2 mixed the vocational training problems provided by institutions specialized in training children with disabilities. Participants 10 and 16 sources of knowledge were the model of care applied abroad. The NGO who oriented participant 15 was her source of knowledge, she created a hub for orienting families of children disabilities.

Table 23: Unmet need, the model and organizational solution

Participant	Unmet need	The model	Project Name
2	Lack of coordination and geographical scattering	Integrated socio-medical care services.	Creation of socio-medical center inside a school.
2	Lack of inclusive vocational education for persons above 17 years old	University faculty offering non-conventional program.	Creation of an inclusive university program.
10	Lack of inclusive school admitting autistic students	School model operating abroad	Creation of an inclusive socio-medical center for Autistic Children inside a regular school.
15	Lack of orientation for parents with children with disability on where to find care providers	NGO specialized in hearing impairment care.	Creation of disability hub inside the pediatric yard of a medical university
16	Lack of a clear follow up plan for children with down syndrome	A home-based treatment program prepared by a multi-disciplinary team practicing outside Lebanon.	Creation of an NGO working on treatment protocols.

Source: Prepared by the author

Network as a source of knowledge

In addition to the model presented previously, the participants benefited from their social and professional networks.

The participants have their prior knowledge related to healthcare, they are the parents of children with disabilities, and they are resilient. Through resilience they were able to mobilize their social network to get information and knowledge to solve their problems. For example, participant 2 relied on her family network to identify physicians abroad; participant 16 knew about the home-based program through a friend.

The professional network is also an important source of knowledge: for example, participant 2 who is a public health researcher in a medical university campus knew about psychomotor therapy from the psychomotor therapy department available on the university medical campus. She also knew about the non-conventional programs offered through her university colleagues.

The analysis of our empirical data through lens of Cohen and Levinthal (1990) model of absorptive capacity theory revealed similarities and differences. We identified two similarities and four differences. The similarities are: 1- the prior related knowledge and 2-the presence of a source of knowledge. The differences are: 1- the regime of appropriability, 2-the unmet need, 3-the resilience context, and 4- the reactivation loop.

The first difference is the regime of appropriability which is irrelevant to our model since the objective of the participant is to spread the knowledge and allow others to benefit from his or her organizational solution. The parents created solutions to solve their problems and “to help

other families having the same problem” (participant 16). Because of its irrelevance, we excluded it from our model.

The second difference is the unmet need. Cohen and Levinthal’s (1990) model does not mention activation triggers while our empirical data reveal that the process of creating organizational solution was activated by an unmet need.

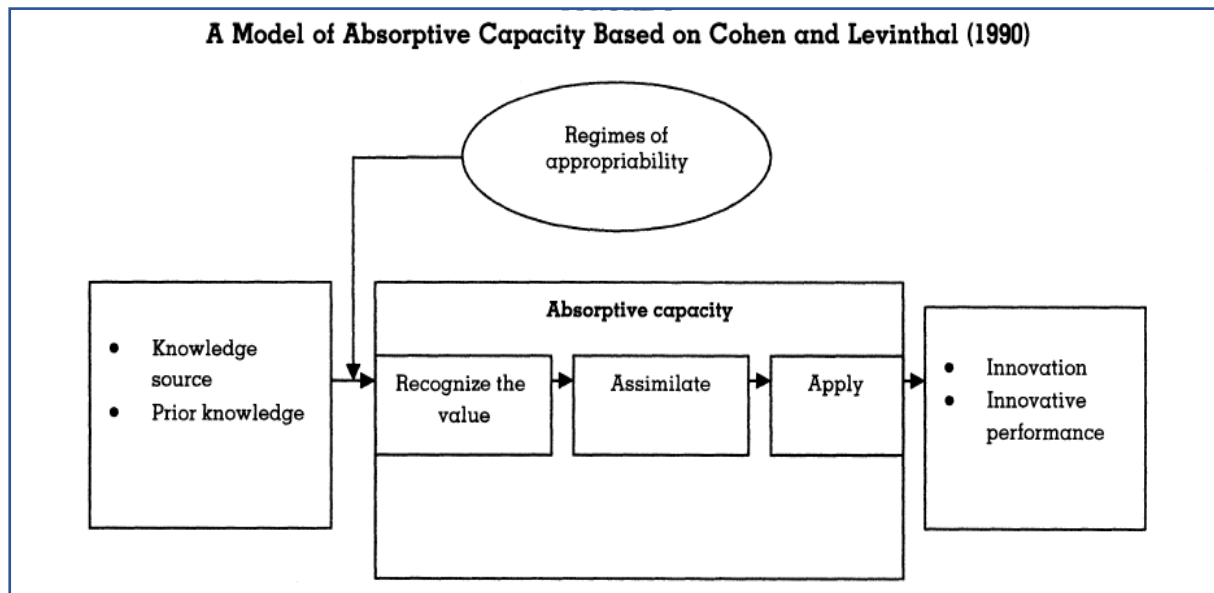
The third difference is the resilience context. According to our analysis, the participants passed into the grief cycle, then they adapted resilience processes before creating the organizational solutions. Resilience is needed all through the process. Our results reveal that the informal knowledge broker was engaged in negotiation, human resources recruitment, launching the project and following up its performance. A traumatized individual would not be able to innovate, to communicate clearly, and to solve problems. These are resilience processes that pertained through all the process.

The fourth difference is a reactivation loop. Each time the participant faces a new unmet need the process is reactivated such as the case of participant 2. This participant created a socio-medical center inside an inclusive school to facilitate the coordination of services and reduce the commuting burden of the parents, later where she noticed a new challenge; young individuals with disabilities would be accepted in inclusive schools nor universities. She created a new project inside a university campus to solve this problem.

Based on these findings and inspired by Cohen and Levinthal’s (1990) model, we propose a refined model to shed light on the factors that emerged from our empirics affecting the absorptive capacity induced by an informal knowledge broker.

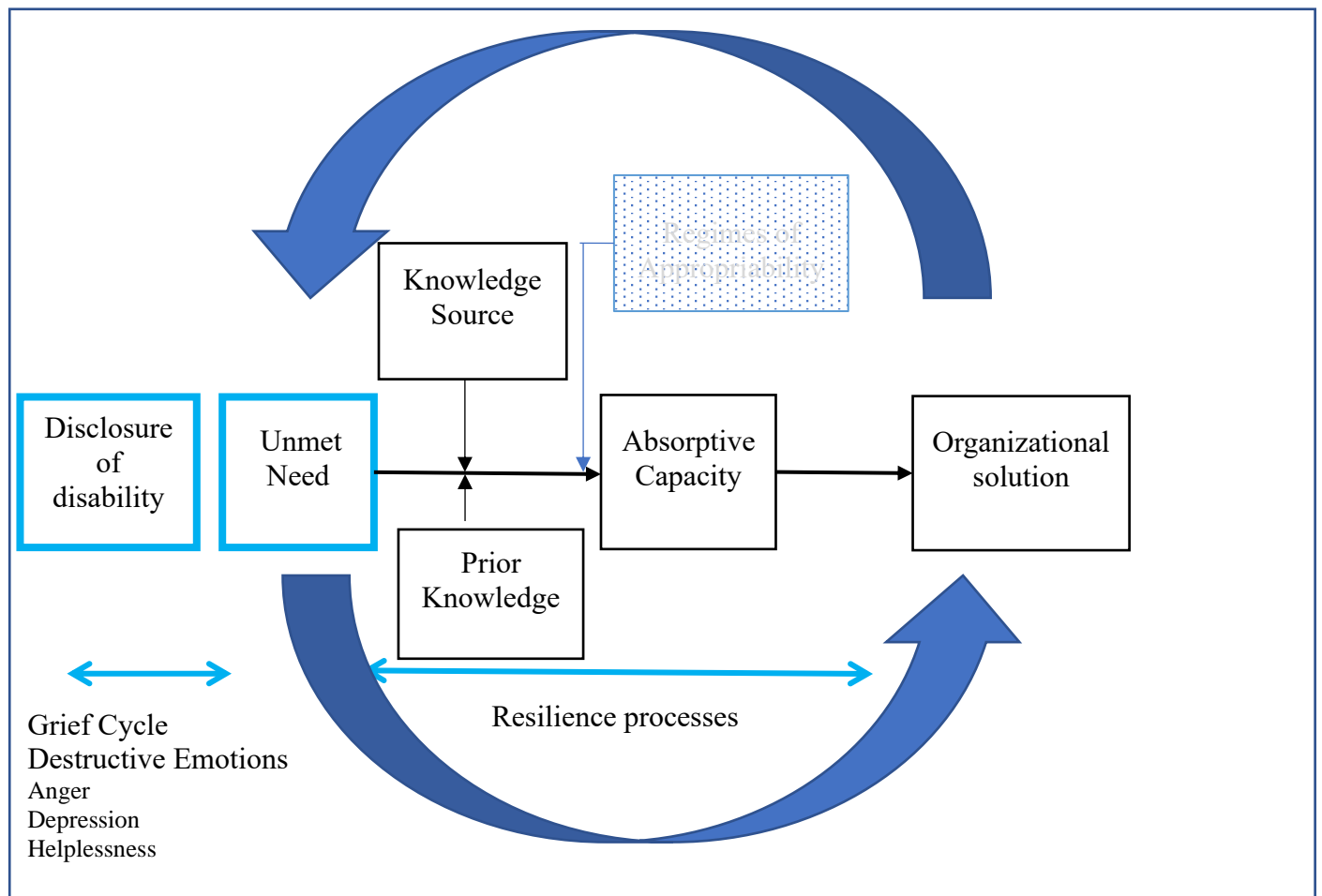
As a reminder, figure 15 presents Cohen and Levinthal's (1990) model and figure 12 presents our refined model which is based on this model.

Figure 15: Cohen and Levinthal (1990) model







Source: (Todorova & Durisin, 2007)

Figure 16: Preliminary model inspired from Cohen and Levinthal (1990)



Source: Prepared by the author based on Cohen and Levinthal (1990)

New element	  
Not apparent in our model	

5.4.From analyzing compassion organizing to compassion brokering

The analysis of our results revealed four collective organizational solutions created by four participants. The participants challenged by an unmet need, they suffered because they need to have a care path for the treatment of their children (participant 16), or they need to know where to find services and providers (participant 15), or they need to admit their children to educational institutions while keeping their socio-medical therapies ongoing (participants 2 and 10) , or they need to prepare their children to become independent and earn their income (participant 2) .These participants benefited from their prior knowledge and source of knowledge, and they invented an organizational solution. They created ideas to solve their problems as participant 10 explained that when she failed to find an inclusive school that provides socio-medical services for children with autism, she decided to “*create one.*” Resources are needed to transform an idea into a project. Resources are knowledge, human capital, fixed assets, and others. The participants identified the organizations that have the resources needed for their projects and they approached them to become hosting organizations. In section 5.3, we have presented the process through which the four participants become informal resilient knowledge brokers. These participants succeeded in developing their projects inside organizations.

We argue that these participants were able to make the others notice and feel their pain and response to it in a collective manner. Though in chapter 3, we have proved that the system does not have the social architecture, nor the capability of emerging and organizing compassion; the analysis of the empirical data shows that these four participants have succeeded to trigger organizational compassion.

These emergent findings pushed us to study in which manner these participants were able to trigger an organizational compassion process despite the non-compassionate system. Our analysis identified two emergent roles that contributed positively to organizing compassion. First, the emergent symbolic role of the hosting organization representative. Second, the emergent role played by the participant in calling for help, managing the project and brokering emotions.

Section 5.4. aims to analyze the emergence of compassion in the organizations where the ideas have been implemented. Section 5.4.1. explains the created symbolic roles of the agents representing the hosting organization. Section 5.4.2. explains the created role of the participants and their effects on compassion organizing.

5.4.1. The helpful director: an emergent contextual symbolic role.

Triggering compassion organizing processes in a non-compassionate system has challenged our theoretical contribution claiming that in the absence of social structure compassion can be organized. The key questions are in what manner the four participants have been able to convince the university board, the school directory, the other pediatricians to adopt their ideas. Therefore, we need to analyze the process that made the secretary of the pediatrician ward, or the university hospital physicians, or the university board or school director willing to help others. We have identified the act of accepting to host such project as an emergent compassionate response. We argue that the hosting organization notices the anguish of the participant, feels it, and responds to alleviate it. Organizations are usually represented by their members and each of the four organizational solutions reveals the crucial emergent role played by the agent presenting the organization.

To analyze this compassionate response, we refer to Madden's et al (2012) theory on emergent compassion capacity and the importance of the agent in a complex adaptive system.

Our analysis reveals that the agents representing the hosting organizations have similar roles to that of the dean in Dutton's et al. (2006) case. We have resorted to Dutton et al. (2006) theory on compassion organizing that highlighted the importance of the emergent features specifically the created roles and the symbolic leadership actions in fueling compassion organizing.

Table 24 below presents the representative of hosting organizations per project.

Table 24: Hosting organizations representatives

Participant	Representative of Hosting organization	Project name
2	School director	Creation of socio-medical center inside a school.
2	University board	Creation of an inclusive university program.
10	School director	Creation of an inclusive socio-medical center for Autistic Children inside a regular school.
15	Physicians	Creation of disability hub inside the pediatric yard of a medical university
16	Physicians	Creation of a treatment care path for children with down syndrome.

Source: Prepared by the author

Madden et al (2012) noted that the spontaneous individual response of an agent can change his role and leads to the emergence of organizational compassion without managerial decisions. Our empirical data shows that the spontaneous action of a “*helpful*” school director has led to the creation of the socio-medical center for Autistic Children inside the regular school.

“I know nothing about inclusion nor autism but if you can do something go ahead. I support you. I would give us a space where we could do whatever we want.”
(Participant 10).

Dutton et al. (2006) define leaders’ actions as actions in which the leaders intend to influence their followers behaviors or actions. The leaders expect the followers to act in a similar way. The dean offered a public donation during a formal event that boosted the compassion organizing process (Dutton et al., 2006). The action of the director who allocates a classroom for autistic children and asks the school staff to collaborate with the participant to ensure the success of the project is similar to that of the dean. The role of the leader extends beyond the action itself, it has a symbolic meaning and might become a story of compassion and care inside

the organization (Dutton et al., 2006). The response goes beyond a single compassionate action to a compassionate organizational solution. In our example, the director of the school noticed the pain of the participants and transformed his empathetic concern into an emergent organizational compassionate response. We suggest that the symbolic action of the leader facilitates the emergence of organizational compassion. An idiosyncratic act of compassion performed by the director has been transformed into a long-term organizational solution inside the school.

We conclude that the representative of the hosting organization noticed the pain of the participants who are outsiders to the organization and allowed them to participate in organizing compassion. Therefore, we contribute to compassion organizing literature and we theorize that leaders' spontaneous agentic response allows the organization to notice the pain of an outsider, feel it and to respond to alleviate it through creating compassionate organizational solutions.

In section 5.4.2., we analyze how the organization allowed the participant, who is an outsider, to become an informal member of the organization and participate in the compassion organizing process.

5.4.2.The informal compassion brokers

In the previous section, we argued that the leader symbolic agentic role can launch compassion organizing process in the organization to reduce the pain of an outsider.

Our empirical data reveals that the participants, despite being outsiders, were involved in the compassion organizing process as informal members of the organization. For example, participant 2 pitched the project to the university board members. She recruited the special educators that will manage the daily activities of the university vocational center. She approached specialists to develop a curriculum customized to the need of the students. She contacted parents of persons with disability to present her project and to encourage them to enroll their children in the university vocational programs. She followed up the performance of the program.

Table 25 below presents the role played by each participant in activating and mobilizing compassion.

Table 25: Participant contribution to compassion organizing process

	Participant 2	Participant 10	Participant 15	Participant 16
Activation of compassion organizing process	Pitching the project to university board members.	Asking for help from the school director.	Approaching colleagues and asking them to prepare a database of providers inside the system.	Approaching the pediatricians in a medical university hospital asking for a treatment care path for children with Down syndrome.
Mobilization of compassion organizing process	<ul style="list-style-type: none"> •Preparation of customized curriculum. •Recruitment of specialists. •Following up •Encouraging families to enroll their children. 	<ul style="list-style-type: none"> •Preparing the physical classroom (painting the walls, class and office equipment, educational materials). •Customization of resources (one parent donated toys, another brought a used computer) •Recruiting specialists and following up their performance. 	<ul style="list-style-type: none"> •Collecting information about NGOs dealing with hearing disabilities in Lebanon. •Referring the parent of the child to the ward secretary to get information. •Identifying the disability of the patient and referring him to the specialist. 	<ul style="list-style-type: none"> •Collecting the treatment information. •Printing the care path document mentioning the treatment needed per age, the follow up tests required at each age. •Providing the pediatricians with copies to be distributed to concerned families.

Source: Prepared by the author

The participants created roles similar to that of Kellie in Dutton's et al. (2006) case. Kellie created her expeditor role and activated compassion organizing process. She mobilized compassion organizing by communicating the particular needs of the fire victims such eyeglasses, clothing of specific size or class notes. Dutton's et al. (2006) defined created roles as "informal, unofficial roles that are created during the compassion organizing process to allow certain individuals to monitor and direct the unfolding process."

We suggest that the disclosure of the disability of the children is the trigger of the process emotional brokering process. The parents are traumatized by the disclosure of the disability of their children. Being in an inequitable, uncompassionate, and fragmented healthcare system,

they felt lost, unsupported, financially abused, uninformed, and discouraged. In short, they felt deprived from a basic right since healthcare is a basic right according to the United Nations treaties.

At this level, the parents experienced negative destructive emotions. They feel angry, depressed, helpless. They are traumatized, and they did not receive help from the system. Thus, the parents enter into a grief cycle denial, anger, bargaining, depression, and they finally reach acceptance. At this stage, the grief cycle ends.

Accepting their situations, the participants start to develop resilience processes. Their belief systems provide a meaning to their suffering. They empower themselves by the can-do spirit and start mobilizing their social and economic resources to identify solutions that can alleviate some of their pain. They start to communicate their feelings and proceed to problem-solving techniques. They become resilient.

The parents identify a source of knowledge, absorb the relevant knowledge, build on their prior knowledge, and create an innovative idea that can contribute positively to their situations. At this stage, the participants are informal resilient knowledge brokers.

Being informal resilient knowledge brokers, they approach the organization to implement their projects. They clearly communicate on their need, collaborate to solve the problem, and mobilize social and economic resources in summary, they use the resilience processes and present the innovative idea to the directors of the organization. The latter noticed the pain and instinctively responded to alleviate it by allowing the informal resilient knowledge broker to create an informal role inside the hosting organization in order to implement his or her idea. It is worth noting that the innovative idea is that of the informal resilient knowledge broker and

not the hosting organization. We assume that due to the professional status of the informal resilient knowledge brokers (researcher, physician, pharmacists, healthcare provider), the directors trust them and perceive them as credible.

5.5.Towards an organizational emotion brokering model

In the preceding parts of our research, we have used several frameworks to study the object of our thesis. We based the analysis of our empirical data on two main frameworks: 1-Dutton et al. (2006) on compassion organizing and 2-Cohen and Levinthal (1990) on absorptive capacity. Dutton's framework was used first to understand the effects of the social architecture of a highly fragmented system on compassion organizing. The analysis gave us partial understanding of the phenomena under study. We, therefore, relied on Cohen and Levinthal (1990) framework to complement our understanding of how some individuals succeed in creating innovative ideas. Again, when confronting our empirics with this literature, we only gained a partial view of the process. We noticed however, that some features of Dutton's framework which did not appear in the first step of the analysis, emerged could bring meaning to our understanding of the phenomena if associated to Cohen and Levinthal (1990) framework. Thus, we revisited our empirical once again through Dutton's lens. This allowed us to identify important emergent features of compassion organizing, when combined to Cohen and Levinthal (1990) framework gave a clearer understanding of the process of creating organizational solutions.

In the first part of our research, the analysis of our data based on Dutton's framework (2006) showed us that the social architecture of a highly fragmented system, like the Lebanese healthcare system, hinder compassion organizing. The Lebanese healthcare system is dominated by values of detachment and depersonalization, bureaucracy and clinical review routines, lack of network and interconnected roles which differs with the values, routines, and

networks of the social architecture of organization as defined in Dutton's et al. (2006) framework.

Despite the fact that the social architecture of the highly fragmented Lebanese healthcare system was lacking and therefore inhibited compassion organizing, our empirics revealed that the even though the parents, were traumatized by the disclosure of the disability of their children, they embraced professional roles such as expert- patients and case managers. A deeper analysis revealed that some "compassion oases" were transformed into organizational solutions. Thus, we found that some parents were able to go beyond these two roles to create organizational solutions.

Researches on absorptive capacity focused on the organizational level though this capacity is rooted in the individual capacity (Cohen & Levinthal, 1990). Few researches studied the role of the individual (Lane et al., 2006; Schweisfurth & Raasch, 2018), mostly the employee of the organization, while some studies considered the client as a source of knowledge. Our review did not identify studies showing the role of an individual outsider to an organization, such as the parent, endorsing the role of a knowledge broker.

In our research, the parents were more than a source of information to the organization. They were involved in applying the knowledge acquired inside an organization and as an informal knowledge broker contributed to the absorptive capacity of the organization. Parents identified the unmet need, had the "can-do-spirit" and made meaning of this adversity. They mobilized their resources to get the knowledge needed to implement their ideas. Through their brokerage position, they generated a creative idea by incorporating the knowledge acquired from one group or network into another group. Being part of various networks enables the participant to

draw upon connection with others to allow the flow of resources needed for innovation (Williams & Shepherd, 2018). They are therefore considered resilient as defined by Walsh (2002, 2003, 2016b, 2021). Resilience processes are essential throughout the process of creating new projects.

The parents are, therefore, the implementers of acquired knowledge. They have identified an unmet need, a model, and an idea of an organizational solution. They benefited from their previous knowledge, they identified a receptive hosting organization and resources needed for the implementation of their solution. This suggests that all the parents have followed a processual approach in developing their organizational solution. This process is schematized in figure 16 above.

In our second part, a deeper analysis of this process led us to identify the major role played by the director of the hosting organizations as a catalyst the shifted this individual compassionate response onto an organizational solution in a highly fragmented context characterized by distress organizing instead of compassion organizing. The director of hosting organization as a symbolic leader (Dutton et al., 2006) was able to activate and mobilize compassion in highly fragmented systems. Our identification of this role reverted us to Dutton et al. (2006) emergent features notably symbolic leaders' actions. Therefore, we amended our previous model (Figure 16) to include compassion organizing process triggered by the director of the hosting organization as a main element of our final model.

Our research diverts from that of Dutton's et al. (2006) at the level of the relationship between the participant and the hosting organization. In Dutton's et.al. (2006), the students and teachers are members of the university. In our case, two of the participants belong to the hosting

organizations network (participants 2 and 15) and the other two (participant 10 and 16) do not belong to the hosting organizations.

As previously presented, the roles of these participants surpassed making the pain noticeable, they performed informal and unofficial roles inside organizations although they are outsiders to the organization. Compassion organizing literature lacks from research pieces on how the organizing processes respond to the pain of an outsider (Madden et al., 2012). Moreover, we could not find any work addressing an outsider who became member of the compassion organizing process inside an organization as the participants in our study. Most of the articles on compassion stress the importance of credibility and trust. Trust and credibility are improved when the individual is a member of the same network. He or she can enhance collective noticing, feeling, and responding to pain while networks also facilitate resources identification, extraction and calibration (Dutton et al., 2006; Shepherd & Williams, 2014; Williams & Shepherd, 2018).

In an attempt to explain the reasons for trusting the participants and allowing them to perform informal unofficial roles inside the hosting organization representative, we went back and forth between the empirical data and the literature. The literature stresses that compassion organizing requires trust and credibility (Dutton et al., 2006; Lilius et al., 2011; Madden et al., 2012; Shepherd & Williams, 2014) that arise from networks. Our empirical data reveals that the organizations' representatives and the participants do not always belong to common networks. However, the four participants in our research have been recognized as professionals with an expertise that gives them legitimacy.

Table 26: Profession of the compassion brokers participants

Participant	Profession
2	University professor- Public Health
10	Pharmacist
15	Pediatrician
16	Healthcare Provider

Source: Prepared by the author

This notion of “professional with expertise” reminded of Mintzberg (1993) definition of a professional “person is duly trained and has the power of expertise”. According to Atzeni (2017), professionals gain social status because of their responsibilities. This status gives legitimacy and credibility to the professional (Atzeni, 2017). We suggest that the representatives of the hosting organization trusted the participants because they were “professionals.” We also suggest that the participants, having the professional culture (Urasadettan et al., 2018), initiated complementary cooperation.

Individuals in pain create informal unofficial roles to ensure activation and mobilization of organizational compassion. At this stage, the resilient knowledge broker becomes an informal organizational compassion broker. Resilience is essential to informal knowledge brokering and the resilient knowledge brokers can trigger compassion organizing inside an organization once they are able to attract the attention of the leader to their pain. The leader’s involvement creates a symbolic feature that fuels the process of compassion organizing.

Compassionate has positive effects on the emotions of individuals and on the organization (Simpson et al., 2020). It also has positive effects on the person in pain, the ones contributing to compassion and to those witnessing it (Lilius et al., 2003; Madden et al., 2012). Compassion enhances pride, gratitude, and satisfaction. These emotions are shared between the person

performing the compassionate act, the receiver of the act and the witness of the act. Thus, the emotions have been transformed from negative destructive emotions to positive (Dutton & Workman, 2011). The organizational emotion broker transforms negative emotions to positive emotion through identifying innovative ideas and turning them into organizational solutions. Thus, the informal organizational compassion broker becomes an organizational emotion broker. To succeed, the emotion broker has to master resilient processes, has to have prior knowledge and must be willing to perform an informal unofficial role. At the organization level, the presence of an agentic compassionate leader at the head of the hosting organization is a condition of success.

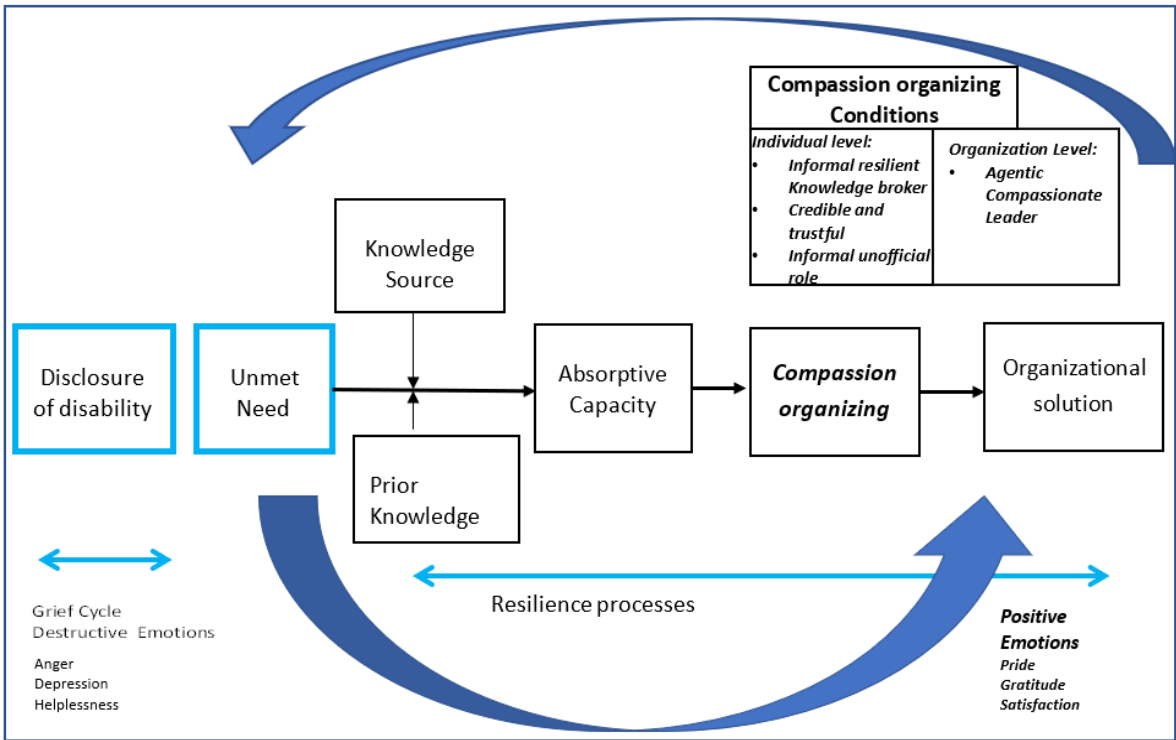
In this chapter, we have based our analysis and discussion of our research topic on several models and frameworks. This allowed us to address our research question from different perspectives since our empirics led us to believe that no single framework can grasp all the elements in one model. This gave us a better understanding of the phases lived by the parents in their experiences and thus, a holistic view of the process of organizational emotional brokering.

The emergent organizational emotions brokering model we propose results from our abductive approach: the elements of the model emerge from literature and the field. It includes fundamental elements borrowed from the frameworks used and from our results presented above. This model should allow the reader to develop a holistic understanding of how parents faced with adversity become able to transform grief and its destructive emotions into positive emotions created from compassion solutions. Future researchers will also be able to investigate the model, test it, and transpose it to other contexts with an ultimate aim of improving it.

The model aims to explain how the parents of children with disabilities go through the process of identifying their unmet need and resources, absorbing relevant knowledge triggering compassion organizing to alleviate sufferings. This model (Figure 17) follows a processual approach of the key events identified in our collected data. As previously mentioned, it builds on our previous model (figure 16) driven from Cohen and Levinthal (1990) and enriches it with features from Dutton et al. (2006) compassion organizing framework.

This model is built on three assumptions. The first assumption is that having a child with disability is a traumatic event (Walsh, 2021). The second assumption is that compassion is an innate human instinct to response to the suffering of others (Dutton et al., 2006). The third assumption is a fragmented inequitable healthcare context.

Figure 17 : Organizational Emotions Brokering Model inspired by Cohen and Levinthal (1990) and Dutton et al. (2006)



Source Prepared by the author based on Cohen and Levinthal (1990) and Dutton et al. (2006)

New element form Cohen and Levinthal (1990)	<div> <div></div> <div>↔</div> <div>↻</div> </div>
New element from Dutton et al. (2006)	All elements in bold and italic

Summary of chapter 5

The diagnosis of disability is an intense traumatic event (Thwala & Hlanze, 2015) to the parents. Each participant experienced his or her grief differently. Most participants passed through the grief cycle, they denied, they experienced anger, they bargained, they passed through depression before being able to accept that the disability of their child is permanent. When they accept reality, the healing process starts. They became stronger, they adapted to the changes, reorganized their roles, and made new relationships. The participants shared their experiences with others and started to develop resilience.

This chapter presented the passage from a traumatic situation to organizational emotional brokering. Started by the grief process, to pass to resilience before brokering knowledge and triggering organizational compassion. A process through which destructive emotions were transformed to positive ones.

It showed that the participants were informal knowledge brokers and that their role goes beyond intermediation or knowledge transfer among network members (CHSRF, 2003) since it contributes to innovation by facilitation knowledge integration (Ziam et al., 2009). It surpasses the identification of relevant information, to its acquisition, assimilation, and exploitation to create innovative solution (Cohen & Levinthal, 1990; A. B. Hargadon, 1998; Todorova & Durisin, 2007; Zahra & George, 2002; Ziam, 2010a). Our results showed that the parent was an informal knowledge broker and he or she contributed to the absorptive capacity of the organization. We analyzed how the informal knowledge broker, being an outsider, was able to implement his or her project. We argue that compassion is the “magic stick” that opened the door of the hosting organization despite being in a non-compassionate system.

Summary of Part II

Part II answered our research questions on how parents become resilient and how do the parents of children with disabilities manage to find solutions to the challenges they have experiences.

The parents were shocked by a traumatic event, the disclosure of the disability of their child. They were also faced by the inequity and lack of compassion of a highly fragmented system. They entered the grief cycle. Later, they started to adopt resilience processes and started to absorb knowledge. They had the idea of a solution to their needs and wanted to turn it into an organizational solution. At this stage, they were transformed from a resilient person to an informal knowledge broker.

To turn it into a project, they need resources available in organizations. Thus, they find themselves in a need to trigger compassion organizing inside the organizations and to convince them to implement the project. At this stage they are the compassion broker.

Succeeding in convincing the leader of the organization, the idea becomes a reality. Since compassion trigger positive emotions to those involved or witnessing a compassionate act, thus we were transformed into organizational emotion brokers.

The metamorphose cycle shifted the parent from a traumatized individual to an organizational emotion broker.

General conclusion

At the end of this thesis, we would like to remind the objective of our study and of the most prominent results. We would then present our contributions, and we will conclude with the limits and future research perspectives.

Objective of the thesis

The objective of the thesis is to better understand the challenges faced by parents of children with disabilities in a highly fragmented healthcare system, such as Lebanon, through their own experiences. Using a qualitative, phenomenological approach twenty-nine semi structured interviews were conducted in Lebanon to study the object of our research. The main research question is : *“How the parents experience and address the challenges raised by having to care for children born with disabilities in a highly fragmented system when rejecting institutionalization?”*

The thesis aims to address the four research sub-questions:

1. What are the challenges experienced by parents of children with disabilities in highly fragmented healthcare systems?
2. How do the parents of children with disabilities respond to the challenges they experience?
3. What is the process followed by parents of children with disabilities to become resilient?
4. How do the parents of children with disabilities manage to find solutions to the challenges they have experienced?

On the methodological front we initiated a series of key informant interviews, providing our research with an inductive start and feeding our analysis thanks to an abductive approach, to identify and in-depth analyze both the emerging role of knowledge broker of some parents and the process by which compassion organizing had been initiated by the parents of children with disabilities, through a diversified sample of types of disabilities, in the context of a highly fragmented healthcare system and fragile country, Lebanon.

Main Results

We answered our first research question by analyzing and characterizing the challenges faced by the parents of children with disabilities in a highly fragmented system. We found that in a highly fragmented system the financial burden and lack of support induce the major burden to parents of children with disabilities. We also presented concrete expressions on the inequity resulting from this highly fragmented healthcare system. In addition, we propose some key elements referring to the roots of the lack of compassion organizing in such a context.

Concerning our second research question, our research also reveals that the parents of children with disabilities informally embraced professional roles such as the expert patient and the case manager to overcome these challenges.

Regarding our third research question, our research shows that the parents of children with disabilities passed through a grief process after the disclosure of the disabilities of their children. Then, they made meaning of the adversity, mobilized resources, and developed communication and problem-solving processes.

Addressing our fourth research question through a processual approach, our research reveals that the parents of children with disabilities became informal organizational emotion brokers by absorbing knowledge and triggering compassion in a hosting organization that they have chosen.

Contribution of the thesis

The findings of the research presented in this thesis provide multiple practical, empirical, and theoretical contributions.

From a practical perspective, the research leads to a series of recommendations. The first one is to train healthcare existing and future professionals on how to inform the mother having given birth to a child with disabilities. This may be done by integrating an applied psychology course into the school of medicine curriculum, as it is in some faculties like in Nantes.

The second recommendation is to make a place for expert patient's parents in the healthcare team and this also implies to train medical and allied profession staffs and students how to welcome this new actor and to learn to work with him/her.

The third recommendation is to introduce a care path manager who might be one of the expert patient's parents. This would contribute to reducing the financial vulnerability of the patient's parent and valorize the expertise developed by recognizing it into the formal healthcare system.

From an organizational perspective, the main contribution of this thesis is that it investigates experiences of parents of children with disabilities in complex and highly fragile contexts such as Lebanon and in a fragmented healthcare setting. Nevertheless, we suggest that the findings may be relevant in other healthcare systems. So, we can propose our findings in a checking list

to assess other systems and call for future research pieces to explore the relevance of this list in other contexts.

The study is also the first to adopt multiple frameworks to understand this phenomenon through a processual approach. It extends the work done by other scholars on absorptive capacity and compassion organizing frameworks.

Regarding absorptive capacity literature, the research is the first to examine the process by which an individual, outsider to an organization becomes a knowledge broker. Although, we could find in the literature some studies on how the employee in the organizations contribute to knowledge brokering, (Lane et al., 2006; Schweisfurth & Raasch, 2018), our literature review did not identify studies on the knowledge brokers as outsiders to organizations. Moreover, our research shows that in our specific context, the “regimes of appropriability” in the Absorptive capacity model of Cohen and Levinthal (1990), was irrelevant. However, we identified from our empirical data an activation element, non-existent in the previously mentioned model, which is the trigger to knowledge brokering. This appeared as an essential element of our model.

As to the contribution to compassion organizing literature, our results suggest that initiating a compassion organizing process inside an organization may be possible under two conditions: 1-the suffering person (whether an outsider or an insider to the organization). has to be a resilient knowledge broker who is going to perform informal and unofficial roles inside the organization and 2-the organization should have an agentic leader capable of noticing and feeling the pain.

Our final contribution is the organizational emotion brokering model that integrates the ability of individuals in pain to identify their unmet need, absorb relevant knowledge, locate resources, and trigger compassion organizing process to alleviate their own suffering and that of others. This model highlights that there is a process through which an outsider goes through to propose an organizational solution to respond to an unmet need. This process incorporates absorptive capacity, resilience and compassion organizing as well as transforming destructive emotions into positive ones.

Strengths and limitations of the research

The strength of this research lies in the rigorous qualitative approach used to explore a complex phenomenon such as the experiences of parents of children with disabilities in highly fragmented and fragile contexts in a process-based approach. Moreover, the position of the researcher as a parent of a child with disability facilitated access to the field and created a secure environment for the parents to share freely their experiences. Participants demonstrated a positive attitude, a willingness to collaborate and an availability for interview sessions. So, this enabled us to collect an extraordinary empirical material with thick descriptions of the lived experiences of the parents facing the fragmented Lebanese healthcare system.

This research is not exempt from limitations. This work focuses on a specific context which makes it difficult to transpose the results to other contexts; however, our aim was not to generalize our findings but to understand the experiences lived by the parents of children with disabilities in- depth.

Future research avenues

This research can serve to favor future research on absorptive capacity and compassion organizing. Several concepts were studied from both frameworks which would need further exploration. Future research can build on the role of the “informal knowledge broker” in contributing to the absorptive capacity of organization of different types of structures. Furthermore, additional research on emotion brokering in different types of organization structures would bring an added value to organization literature.

Research on the sustainability of the organizational solutions would help in improving the “Organizational emotional brokering model”.

Moreover, research that include the perspective of other stakeholders such as the healthcare providers and the directors of the organization could enrich the understanding of the complex phenomenon.

Different country context and health systems would also provide specific contextual and environmental elements that may impact the informal organizational emotional brokering process.

This research serves to favor future research on the phenomenon through different theories lenses such as the CARE theory and / or the stress theory.

Finally, our work calls for other research to confirm or infirm our findings which are exploratory by nature and focused on four emotional brokers resorting to the same care of documenting the research context.

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Titre : Résilience, Capacité Absorptive et Compassion: Cas des parents d'enfants handicapés dans un système de santé hautement fragmenté.

Mots Clés : Inégalité des soins, Résilience, Courtier du savoir, Capacité d'absorption, Compassion, Organisation de la compassion, Courtier des émotions organisationnelles, Enfants handicapés.

Résumé: Les systèmes de paiement tels que la T2A (Tarification À l'Activité) pour les soins aigus hospitaliers ou les systèmes de paiement à l'acte incitent les professionnels de santé à augmenter les services qu'ils peuvent facturer. Cela a un impact sur la qualité des soins ; l'éthique professionnelle est remise en cause et des phénomènes de réification peuvent se développer. La concurrence entre les prestataires de soins s'accroît ainsi que la fragmentation et la discontinuité des soins qu'elle favorise. Les personnes qui souffrent le plus de cette fragmentation sont celles qui ont besoin de l'intervention de plusieurs prestataires de soins sur de longues périodes, comme les personnes handicapées.

Cette recherche vise à explorer les défis soulevés par la fragmentation d'une perspective patients et comment il devient possible de surmonter les maillons manquants de la chaîne de soins, à partir du cas des enfants nés avec un handicap dans un système très fragmenté comme le Liban. Vingt-neuf entretiens semi-structurés ont été menés auprès de parents d'enfants nés avec un handicap. Il est le premier à aborder ce phénomène à travers une perspective phénoménologique et une approche processuelle basée sur de multiples cadres.

L'exceptionnel matériel empirique collecté permet d'identifier les étapes clés de dysfonctionnement du système et d'analyser son impact sur les parents. Les rôles assumés par les parents mettent en lumière de manière informelle les améliorations à apporter au système.

Nos résultats fournissent également une nouvelle analyse des processus par lesquels la résilience des parents se manifeste et des conditions de succès dans lesquelles des solutions d'organisation de la compassion sont initiées et mises en œuvre par certains parents déclenchant une action collective en passant de courtiers de connaissances à courtiers d'émotions organisationnelles.

Cette thèse contribue à l'ensemble de la littérature sur la capacité d'absorption et l'organisation de la compassion, elle modélise également le processus par lequel un individu extérieur à une organisation passe par la conception, l'initiation et la mise en œuvre d'une solution organisationnelle pour répondre à un besoin non satisfait. Ceci conduit à proposer un modèle conceptuel des processus de Compassion Brokering. Cette recherche fournit également une série de recommandations pratiques aux fournisseurs de soins de santé actuels et futurs.

Titre : Resilience, Absorptive Capacity and Compassion: The case of the parents of children with disabilities in a highly fragmented health care system.

Keywords: Inequity of care, Resilience, Knowledge broker, Absorptive Capacity, Compassion, Compassion Organizing, Children with Disabilities

Abstract : Payment systems such the French T2A (Tarification À l'Activité) for hospital acute care or fee-per-service systems are incentivizing healthcare professionals to increase the services for which they can bill. This impacts the quality of care; professional ethics are challenged, and reifying phenomena may develop. Competition among healthcare providers increases as well as its fragmentation and the discontinuity of care that it favors. Individuals who suffer the most from this fragmentation are those who need the interference of multiple care providers over extended periods of time such as persons with disabilities.

This research aims at exploring the challenges raised by fragmentation from the patient side and how it becomes possible to overcome the missing links of the chain care, from the case of children born with disabilities in a highly fragmented system such as Lebanon. Twenty-nine semi-structured interviews were conducted with parents of children born with disabilities. It is the first to address such phenomenon through a phenomenological perspective and processual approach based on multiple frameworks. The exceptional empirical material collected enables us to identify the key stages where the system dysfunction and to analyze how it impacts the parents.

The roles embraced by the parents informally highlight the improvements to be brought to the system. Our findings also provide a novel analysis of the processes by which parents' resilience enacts and the conditions of success under which compassion organizing solutions are initiated and implemented by some parents triggering collective action by shifting from knowledge brokers to organizational emotion brokers.

This thesis contributes to the body of literature on absorptive capacity and compassion organizing, it also modelizes the process through which an individual outsider to an organization goes through to design, initiate, and implement an organizational solution to respond to an unmet need. This leads to propose a conceptual model of Compassion Brokering processes. This research also provides a series of practical recommendations to existing and future healthcare providers.