Data Availability Statement: All relevant data are within the paper and its Supporting Information files.

Competing Interests: The Author(s) declare(s) no conflict of interest.

The invisible role of feminine caregivers in Palestine. The Emancipatory Research process as a path towards well-being

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Abstract

The paper aims to analyse the well-being of feminine caregivers in Palestine. In order to do that it explores the outcomes of the preliminary step of the Emancipatory Research (ER) carried out in the "PARTICIP-ACTION" Project (financed by the Italian Agency for Development Cooperation – Ministry of Foreign and International Cooperation, promoted and carried out by EducAid – Inclusive Education and Social Innovation for International Cooperation). The ER is a bottom-up process that promotes a progressive involvement of vulnerable groups of people as researchers at first hand. In case herein considered, the researchers are 30 feminine caregivers of relatives with disability. Starting from their own point of view and their own personal experience, they first selected and then investigated a few dimensions of well-being deemed essential for them to reach a good quality of life.

Keywords: caregiver, disability, well-being, Emancipatory Research, possibilities

Abstract

Questo articolo vuole analizzare la condizione di benessere delle caregiver femminili in Palestina esaminando i risultati emersi nelle fasi iniziali della Ricerca Emancipatoria realizzata all'interno del Progetto "PARTICIP-ACTION" (finanziato da Agenzia Italiana per la Cooperazione allo Sviluppo – Ministero degli Affari Esteri e della Cooperazione Internazionale, promosso da EducAid – Educazione Inclusiva e Innovazione Sociale per la Cooperazione Internazionale). La Ricerca Emancipatoria è un processo *bottom-up* che promuove la progressiva partecipazione di gruppi di persone vulnerabili come ricercatori in prima persona. Nel caso proposto, le ricercatrici sono 30 donne della città di Nablus, *caregivers* di parenti con disabilità. Partendo dal loro punto di vista e

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dalla loro esperienza, queste donne hanno prima selezionato e poi indagato alcune dimensioni del benessere ritenute da loro essenziali per raggiungere una buona qualità della vita.

Parole chiave: caregiver, disabilità, benessere, Ricerca Emancipatoria, possibilità

Introduction

This paper aims to reflect on the key issues emerged in the "PARTICIP-ACTION" Project[4] final evaluation[5] conducted in 2018. The Project was carried out in the West Bank (Palestine), over a period of two years and embraces three fundamental cross-cutting social issues: human rights, protection of the vulnerable groups and empowerment of women. These issues set the background of this paper's topic, which is the vulnerable condition of feminine caregivers of people with disability in Palestine. And to address this theme, the framework chosen is the inclusive and human rights based approach, as well as the multi-perspective concept of well-being, as an indicator of women's quality of life.

This paper develops in these main topics: the condition of women as caregivers of people with disability and the concept of disability in Palestine; the concept of well-being towards *Life Project's possibilities*; the Emancipatory Research (ER) methodology; the process behind the preliminary steps of the ER; some future perspectives proposals. The main focus is on the social and family aspects related to the condition of feminine caregivers and the dimensions of well-being from the caregivers' point of view. Indeed, the research process is based on the personal experiences and aspirations of 30 feminine caregivers involved in the "PARTICIP-ACTION" Project's preliminary steps.

The question is the following: what is the gap between these women's idea of a good life and their real condition?

1. Disability: A matter of human rights

According to the World Report on Disability (WHO, 2011; 2017), in the world, persons with disability are little less than one billion – about 15% of the global population. 82% of them live in countries where there is active cooperation, as identified by the Organisation for Economic Cooperation and Development/Development Assistance Committee (OECD-DAC). Moreover, in the world, 90% of persons with disabilities have no access to service, over 85% are unemployed and less than 4% of minors with disabilities have access to formal education.

Not only these people are nearly always excluded from the advantages of development, but disability is clearly both the cause and the effect of poverty. As a matter of fact, people with disability are subject to discrimination and have no access to equal opportunities. This condition limits their participation in society and entails continuous violations of their human rights. The

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[4] "PARTICIP-ACTION": increasing active participation and social inclusion of people with disability in Palestine through the empowerment of local Disabled People Organisations (DPOs). It is promoted and carried out by EducAid - Inclusive Education and Social Innovation for International Cooperation, in partnership with AIFO, Stars of Hope Society, General Union of Person with Disabilities e Asswat Society and financed by the Italian Agency for Development Cooperation – Ministry of Foreign and International Cooperation. It has got the overall purpose of the Italian Cooperation, as set out in the Three-year Programming and Policy Planning Document 2013-2015 (December 2012).

[5] Evaluation Report led by Alessia Cinotti and Giulia Righini, with the scientific supervision of Roberta Caldin (University of Bologna).

negative attitude of society towards people with disability produces a very strong social stigma, which is reflected in the economic, cultural, political and social life. This is why people with disability can be considered the most marginalised among the marginalised, the most discriminated among the discriminated (Italian Agency for Development Cooperation, 2013; 2018).

With the advent of the Convention on the Rights of Persons with Disabilities (CRPD) in 2006, disability can no longer be assessed only as a healthcare issue leading to health care-focused projects. The CRPD has established the respect for human rights as the founding principle for the protraction of the rights of persons with disabilities. That is also why the CRPD in Article 8 (UN, 2006) specifically acknowledges the need of awareness-raising regarding the issue of people with disability both in society and at the family level. Article 8 underlines the importance of nurturing and fostering respect for rights and dignity, throughout recognising and combating stereotypes, prejudices and harmful practices.

1.1. Society and disability, in Palestine

The idea behind the "PARTICIP-ACTION" Project just comes from the awareness that the Palestinian social context is particularly stigmatising and not inclusive for people with disability. This issue leads also to a stigmatisation towards their caregivers, especially if they are women.

As a prove of that, in Palestine it has not been reached yet full correspondence between social practices and cultures and what granted by Law 4/99[6], which regards the rights of people with disabilities. In fact, the definition of disability mainly refers to physical deficits and their effects on the capability of pursuing tasks: this Palestinian law deviates from the definition of disability provided by the CRPD (UN, 2006)[7], mainly embracing a biomedical approach. Therefore, the Palestinian community reveals still very scarce both culture and awareness-raising on the issue of disability. In this scenario, the risk is the tendency to offer mostly aids or medical assistance to people with disabilities than social and educational support. This hampers both the planning of their *Life Project* and the promulgation of new laws and initiatives based on human rights.

Another demonstration of the distorted social representation on disability is that the official percentage of people with disabilities in Palestine is declared around 2%[8], when the real average is 15%, according to the *World Report on Disability* (2011) and the United Nations Relief and Works Agency for Palestine Refugees (2020). This leads to a potentially high rate of unregistered people with disabilities, especially in rural areas: some families prefer not to register their children as disabled in order not to compromise the family's reputation with the social stigma of disability.

1.2. Women and disability, in Palestine

It is just the analysis of the Palestinian context led by EducAid, which triggered the need for the "PARTICIP-ACTION" Project. After EducAid first investigated the distorted perception of

[6] The Law 4/99 states «The Disabled: Any person suffering from permanent total or partial disability whether at birth or otherwise affecting any of his senses, or physical, psychological or mental capacities to the extent of limiting his ability to respond to his living needs under the same circumstances as lived by the non-disabled» (Chapter One, Article 1).

[7] The CRPD defines the concept of disability as «an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others» (*Preamble*).

[8] Palestinian Central Bureau of Statistics (2021), *Press release on the occasion of the International Day of Persons with Disabilities, 03/12/2021*, City of Gaza.

disability as a cause of social marginalisation and exclusion, they highlighted that this dynamic gets even more evident in feminine caregivers and women with disabilities (EducAid, 2012; 2013).

Women with disabilities are, in fact, victims of a "double discrimination": namely, gender, and disability (Bernardini, 2013; Terzi, 2013). This double discrimination punishes not only women with disabilities but also their entire families (Asch, Rousso, Jefferies, 2001). Feminine caregivers live with both the burden of being women in a severely patriarchal society and the social stigma of being relatives of a disabled person. Indeed, the discrimination is much more serious towards mothers, who are socially blamed to have given birth to a "defective" son or daughter (Trisciuzzi, 2000).

Within the "PARTICIP-ACTION" Project, the feminine caregivers' role is investigated through the Emancipatory Research (ER)[9]. It is a specific research methodology which was carried out by 30 women – both women with disabilities and feminine relatives of a person with disabilities – who lived in Nablus. The group decided to take into consideration the barriers that can preclude feminine caregivers from experiencing the well-being dimensions and to analyse these barriers from the caregivers' point of view.

It is fundamental to underline that their difficult life conditions are heightened also by the political complexity that affects Palestinian society and causes inequalities, such as unemployment, unequal access to public resources and social services.

2. Disability: A matter of well-being

The concept of well-being goes hand in hand with the idea of "health". Nowadays *health* is considered a complex and multi-perspective concept that has evolved in the last forty years thanks to social, medical and scientific achievements. These cultural changes have led to a redefinition of the notion of "health". It is considered both an ongoing process – contextualised in "time" and "space" (Calaprice, 1991; Soutter, 2011) – and an indicator of the quality of life.

Into this wide-ranging framework, the World Health Organisation (WHO, 1948) defines health as a state of complete *physical, mental and social well-being*. In this regard, health is no longer the absence of disease or infirmity, but it is a dynamic human condition strictly related to the life environment. Thus, the WHO perspective leads to the description of health as both a state of *bio-psycho-social well-being* (ICF, 2001) and a *human right* (NU, 2006). WHO's point of view is open to *possibilities* and looks at the future where each person can feel fulfilled, overcome daily life difficulties, have a job and contribute to their community.

Therefore, well-being is about accomplishing everyone's full potential in relation to themselves, the others and the environment they are in. Since well-being refers to the *hic et nunc* state of a person there is another significant step to consider: *well-becoming* (Biggeri, Santi, 2012; Ghedin, 2009; Gordon, O'Toole, 2015; Uprichard, 2008). Unlike well-being, well-becoming is a continuous variation of condition – for example, from a state of ill-being to well-being – through a spiralling motion between past and present, toward a future of new life possibilities (Minkkinen, 2013; UNICEF, 2007). Well-being and well-becoming are, indeed, strongly connected.

This ongoing process includes everybody and so recalls the key principles of the inclusive and human rights based approach. From this perspective, the person with a disability is a ful-

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[9] Within the "PARTICIP-ACTION" Project, three groups led the Emancipatory Research in different cities, Beit Sahour, Nablus and Ramallah. They respectively worked on three specific issues: the access to labour market for women with disabilities, the feminine caregivers' well-being, the role of family for people with disabilities. This paper focus is only on the research on well-being, led by the group of Nablus.

ly-fledged member of the community: the diversity of everybody becomes an ordinary condition in the society (Pavone, 2010).

In this connection, the identity is not only the inner perception people have of themselves, but also the perception they build by being recognized by others. It is a process that provides a sense of belonging to groups and communities. In fact, the value of participation in social life is the core of inclusion, which is an existential *status*, an ethical imperative and a basic right that nobody has to earn. Governments and communities have the duty to remove barriers and obstacles that hinder social inclusion, providing appropriate resources and support to allow people with disabilities to grow in inclusive environments (Stainback, Stainback, 1990). Consequently, social policies that derive from an inclusive perspective have to overcome the idea that facing disadvantages delivering goods and services is a good policy. Instead, they must aim to widen and guarantee the spectrum of individual and collective *capabilities* of choice (Sen, 2005, 2006). Capabilities do not concern mere basic human needs, such as food, health and survival, but full fundamental rights.

Considering the issue of disability, the *Capability Approach* (Sen, 1999) states that the capabilities of a person with disability consist of the range of tangible and effective freedoms granted to that person. Disability is considered *capability deprivation* that has to be read as lack or deficiency in the empowerment processes (Arciprete, Biggeri, 2017; Caldin, 2013). These processes should be held, supported and promoted since they are the pathway towards well-being/well-becoming. In other words, social policies should allow people to overcome their condition of *thrownness* (Heidegger, 1976, It. Transl. 2003). As Heidegger states (*Ibidem*), human beings find themselves *thrown* into the world, meeting and dealing with conditions that they did not choose – such as gender, physical appearance, family context, economical-labour dimension, historical-geographical and socio-political environment. These are elements of randomness that precisely mark the starting point of everybody's existence and, therefore, set an inalienable influence on life choices and possibilities (Caldin, Righini, 2017; D'Alessio, 2011; Shakespeare, Watson, 2002).

The *category of possibility* is deeply linked with every individual's Life Project and aims to widen the dimensions of the quality of life, beyond the *existential thrownness of being* (Bertin, 1975; Bertolini, 1988; Heidegger, 1976, It. Transl. 2003). This is the main challenge of inclusive approach.

3. *The "PARTICIP-ACTION" Project and the Emancipatory Research*

Within the "PARTICIP-ACTION" Project, an Emancipatory Research (ER)[10] was carried out. The ER is a bottom-up process that promotes a progressive involvement of vulnerable groups of people as researchers at first hand. Since disability can be considered as a condition that both causes new vulnerabilities and limits the personal *capability set* (Sen, 2005), the value of the ER approach is just to recognise, valorise and implement the capabilities of people with – and dealing with – disability. As a matter of fact, while the overall research questions concern

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[10] From a methodological point of view, the ER was supported and guided by the Action Research for CO-development (ARCO). ARCO is a university centre offering research, consulting, and training services. It was founded in 2008 at PIN S.c.r.l. (Polo Universitario "Città di Prato", Tuscany, Italy) and it maintains strong connections with the Department of Economics and Management and the Department of Statistics, Informatics, and Applications at the University of Florence. http://www.arcolab.org/en/ (last access: 10.07.20). The professional research in charge of the ER is Federico Ciani, Ph.D., ARCO-University of Florence. In the West Bank, the research involved 60 people, divided in three groups: in Beit Sahour (coordinated by GUPWD) and in Ramallah (coordinated by SHS) the groups were mainly composed of women with disabilities, while the group of Nablus – the one we herein consider – (coordinated by Asswat Society) was mainly composed of feminine relatives of people with disabilities.

marginalisation of the most vulnerable groups of the society, the ER allows people who suffer social exclusion to take part in the activities, share opinions and experiences with professional researchers and reach full entitlement of the entire research process (Campbell, Oliver, 1996; Freire, 1971, It. transl. 2002).

In this case, indeed, the professional researchers are firstly responsible for training the participants on how to conduct a research, but afterwards they just work as facilitators. It is mainly responsibility of the people involved to define the research problem, to collect the data, to analyse and disseminate the results. Following this procedure, these new researchers manage to increase their leadership and decision-making skills as well as their awareness-raising (Walmsley, 2010)

Specifically, within the "PARTICIP-ACTION" Project, the ER was aimed to get to know the marginalisation process through the very personal experiences of both people with disabilities and their feminine caregivers. By sharing and collecting their own stories it was possible for them to identify which barriers hampered full social participation and human rights respect. Here is an active example where the ER aims not only to make people with disabilities and their caregivers active parts of the process, but also to increase their awareness of their human and civil rights. This dynamic represents one of the strongest contact points between the ER and the well-being perspective.

The central importance given to the individuals consents them to move from a present condition of *ill-being* to a state of *well-being* and *well-becoming* – intended as a *projectuality* that is open to infinite *possibilities* (Biggeri, Santi, 2012; Gordon, O'Toole, 2015; Uprichard, 2008).

This process of raising-awareness and empowerment is so significant and unique that this paper mainly focuses on that, rather than on the final results of the ER. For this reason, we take into consideration only the preliminary steps of the ER, such as the methodology processes that support the researchers in defining the topic to investigate and the research problem to face: the preliminary steps are the activities that lay the ground for the ER.

The two preliminary steps herein discussed are the *Participatory Activity*[11] and the *Party-Number Exercise*[12] carried out in Nablus, by a group of women, caregivers of people with disabilities (EducAid, 2015).

3.1. *The ER in Nablus: A closer look*

The women of Nablus involved in the research decided to investigate the *issue of well-being* through the analysis of their daily *time schedule*, with a focus on the *burden of care* – and how it interferes within their everyday activities.

Their first steps of the ER – Participatory Activity and Party-Number Exercise – were designed on the basis of two sets of cross-cutting questions. One set concerned the *amount of time* spent on the different duties connected with the care-taking of relatives with disability and the consequent impact on their quality of life. In particular, the survey targeted mothers, sisters and aunts of people with disabilities who live with and take care of them in a relevant and regular way.

The purpose was to quantify the burden of care that was considered to be responsible for the gap between the women's aspirations for a good life and their real condition.

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[11] The "participatory activity" is a methodology that aims to engage, within the first steps of the research, people who are involved in the research topic: in this case, feminine caregivers.

[12] The "parti-number exercise" is a methodology that aims, as a first step, to make the participants reflect on their own personal conditions in order to get detached from their role of caregivers; and as a second step to embrace their new role of researchers with gained awareness and ownership of the research.

The other set of questions focused on deprivation in terms of *time poverty*. The women were asked to assess whether the quantity and quality of time they spent in their daily activities is adequate to reach a good quality of life. Thus, the research aimed to analyse whether the women lived a restriction in their freedom of choice and possibilities.

4. Laying the ground for the ER: The preliminary steps

In the preliminary steps of the ER in Nablus, the women carried out two different initial exercises in order to lay the ground for the research: The Participatory Activity and the Party-Number Exercise. The idea behind these activities was to help the caregivers raise knowledge, attentiveness and awareness on their condition, as feminine caregivers of people with disabilities.

As already mentioned in the paragraph above, this paper herein mainly focuses on the process underlying these two exercises and the self-reflection implemented by the women involved.

Dimensions	Comments
1. To be safe	It included both safety of public places and at home. The women stressed the presence violence inside and outside at home. Also the Israeli occupation contributed to decreasing safety.
2. To be healthy	Including access to health services.
3. To enjoy stability	It included stability on work and stability from the consequences of the military occupation. It is particularly important for the stability of the family.
4. To be free	
5. To preserve dignity	
6. To have good relations with other family members	Including both nuclear and extended family.
7. To have good relations with friends	
8. To have access to education	
9. To see one's rights respected	It is due also to an effective enforcement of existing laws and international conventions (such as UNCRPD).
10. Satisfaction of basic needs	It was conceived as a prerequisite to enjoy the other dimensions of wellbeing: it is not possible for example to have good relations if you are pressed by the satisfaction of basic needs.
11. To have access to economic resources	
12. To have access to job	To have a job and to be productive is a way to be respected within the society.
13. To have access to culture	It starts within the family.
14. To have access to leisure	The participants stressed the lack of public spaces where it is relaxing and nice to stay.

| 15. To feel the emotion of victory | Both concern personal challenges and the collective situation of Palestinians. |
| 16. To be empowered | It meant to have self-confidence and acceptance of the disability; to take decisions and to see them respected. |

Tab. 1 – Dimensions of well-being identified in Nablus (Source: EducAid, 2015)

4.1. Participatory activity

The participatory activity was based on a data collection of a large-scale survey and group discussions which involved 150 women who were caregivers of a person with a disability. In order to better design the ER, the group of Nablus initially investigated the dimensions of well-being (Tab. 1), which they consider deficient in their lives and nevertheless necessary to reach a good quality of life.

The dimensions identified by this participatory activity can be identified as human, social and civil rights that contribute to reaching the *state of complete physical, mental and social well-being* (WHO, 1948), as indicated in CRPD (UN, 2006). The rights – recognised by the women from Nablus – refer to a whole spectrum of *life possibilities* that look towards the future in a well-being perspective (Camfield, Choudhury, Devine, 2009).

In fact, the participants focused their discussions on many aspects of the life condition of feminine caregivers both at home and in the society. These aspects look indeed at their daily experiences, but at the same time enclose the chance to broaden their gaze towards new awareness of values and rights. For example, analysing women's answers, it clearly appears that the well-being they experienced at home was strictly related to the role of those women in their society: a woman who does not feel respected, safe and free in public places, a woman who has no access to appropriate education, to suitable job, to health services, a woman who has no freedom of choice will hardly find a way to be granted a decent role even at home. Thus, this is a clear sign of a twisted idea of women's social role. And this idea is mirrored also in the family dynamics. And it is even more amplified in the case of feminine caregivers: in most cases, they are isolated at home day and night, they do not have a job and they do not have social relationships outside the family. Feminine caregivers are socially invisible. That is why one of the most relevant dimensions of well-being identified by the researchers is the good relationship with family members, including both nuclear and extended family (Oliver, 1996).

Again, the women from Nablus gave also particular attention to the relationships with friends, neighbours, acquaintances and the whole community. A peaceful social environment seems to be the precondition for the well-being towards the well-becoming: on the one hand, the women considered fundamental to satisfy their basic needs, such as food, clothing and housing; on the other hand, they believed it is essential to live in a socially and politically[13] safe and stable place.

Moreover, together with this preliminary analysis of their condition, the group rose another important focus: the identification of well-being's barriers. It is interesting to notice that the family itself seems to represent an important obstacle to feminine caregivers' quality of life. Even their families can hardly accept the disability (Christian, 2010). Thus, the women live with a deep sense of guilt due to two factors: to be related to a disabled person and to choose

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[13] Considering this point, we shall report that some of the participants state that the Israeli occupation is one of the main causes of the decrease of social and political safety.

to take the role of caregiver. This ill-being is even increased by the women's awareness that the discrimination strongly affects also their relative with disabilities.

It is central to also underline that not only taking care of a person with disabilities is physically, psychologically and emotionally stressing, but also that the presence itself of a disabled person tends to increase the economic vulnerability of the family.

4.2. Party-number exercise

The last data offered is highlighted by the second activity of the ER preliminary steps that is called "parti-number exercise" (Tab. 2). It consists in setting up two scenarios of fictional families (A and B) that have exactly the same characteristics, apart from the presence (family A) or the absence (family B) of a son with disability (severe mobility impairment). This process is enabled by the caregivers' discussion and reflection on these two scenarios (families A and B).

Characteristics	Family A	Family B
Composition	1 father 45 years old	1 father 45 years old
	1 mother 45 years old	1 mother 45 years old
	1 son 15 years old (no disability)	1 son 15 years old (no disability)
	1 daughter 17 years old (no disability)	1 daughter 17 years old (no disability)
	1 son 13 years old with severe mobility impairment	1 son 13 years old (no disability)
Work	Only the father works and has lower intermediate wage (2500 New Israel Schekel)	Only the father works and has lower intermediate wage (2500 New Israel Schekel)
Housing	The family owns her house (no rent to pay)	The family owns her house (no rent to pay)
District	Urban Nablus	Urban Nablus
Religion	Muslim	Muslim

Tab. 2 – Scenarios of the "parti-numbers exercise" (Source: EducAid, 2015)

Both families are composed of 45 a years old father and mother, two sons and one daughter, aged 13 to 17. They both live in the urban area of the city of Nablus, where they own a house. The breadwinners are only the fathers, which earn 2500 New Israel Schekels (NIS).

Through the "parti-number exercise", the 30 researchers identified – starting from their own experiences – the two families' monthly costs (Tab. 3) and time routine (Tab. 4).

After having recognised categories, the women of Nablus allocated both the household budget among several expenditures categories (first step) and the time spent on the different activities of a typical day (second step).

Expenditures Categories	Family A	Family B
Food	600	500
Electricity/Gas/Other basic services	650	500
Education (including fee)	450	300
Health care (including assistance)	600	100
Clothes and self-care	50	200
Transports and communication	120	200
Leisure	30	400
Savings	0	300

Tab. 3 – Household budget identified during the "parti-number exercise"
(Source: EducAid, 2015)

As shown by the data in Table 3, Family A spends more money on food, basic housing services, education, and health care, while Family B spends more on clothes, self-care, leisure, transports and communication.

According to these results, the Family A main costs are on basic necessities: from the data of Nablus women, we can assume that whether the caregiver and the disabled relative stay at home the whole day, the housekeeping expenditures are higher. Moreover, the two categories that require the highest economic budget are education – including school fees – and health/assistance care. The necessity of Family A to invest so much on these two expenditures, leads us to another significant data: the savings. Family A, in contrast to Family B, cannot save any money. Furthermore, indeed, Family A cannot even afford "ancillary" costs, which are not connected to basic needs, but they can be considered fundamental for reaching the self-fulfilment (Maslow, 1962): having time and money to take care of yourself – for example, buying new clothes, having hobbies, doing sports, enjoying free time with friends outside the house etc. – might be a path to reach the well-being/well-becoming. These kinds of activities can give the person a sense of their value that preludes good quality of life (Bradshaw, Hoelscher, Richardson, 2007).

The highest money gap between the two fictional families is related to the category "health and assistance care" and consists of 500 NIS. This means that Family B has more economic chances to invest in their free time and leisure. We believe it is important to underline that these economic chances do not influence the family life only on a material level but have also a strong impact on their future *Life Project's possibilities*.

Activity	Family A	Family B
Rest	5	7
Housekeeping	6.5	5

Active care of son with disability	3.5	0
Care of other children	1	2
Care of other family members	1	2
Work	1	4
Transport	1	1
Social relations	1	3
Passive care of son with disability	4	0

Tab. 4 – Women's use of time identified during the parti-numbers exercise
(Source: EducAid, 2015)

Referring to the second step of the "parti-number exercise" (Tab. 4) – about the time women spend on the different activities of a typical day – we can find some similarities with the results of the first step.

The feminine caregiver of Family A spends more time at home: the longest amount of time is dedicated to the housekeeping and the *active* care-taking of the son with disabilities (10 hours), plus 4 more hours of *passive* care. The 30 researchers involved in the ER said that the caregiver is obliged to stay at home just because the disabled son cannot be left alone even if she has no active care practice to exercise (Murphy, Christian, Caplin, Young, 2007). These 4 hours of *passive care* are a sort of "empty time", in which the caregiver is completely disengaged from any kind of activity. It is just a safe-keeping time, distant from an educational perspective aimed to design a *Life Project*. The number of hours dedicated to the *passive care* could be invested in other life dimensions of the disabled person, such as social and recreational activities, vocational experiences and educational opportunities.

Actually, from the data analysis, it seems that the relationships with the person with a disability is mostly about care. This issue might come from a culture that considers the disability either as a condition of disease or as a condition of infirmity (WHO,1980). Indeed, the direct consequence of this perspective is that the relationships between the caregiver and the person with a disability is focused on assistance and it leads to a condition of *ill-being* that affects both of them. This goes hand in hand with the symbiotic relationship between the woman and the person she takes care of (Chambers, Chambers, 2015). Such a condition hampers the development of autonomy, individuality and sociality for both of them. Besides, the symbiotic relationship does not give many opportunities to live other familiar and social relationships: from the data collected, the more time the caregiver spends with the disabled relative, the less time she spends with other members of her family – husband, "other" children or relatives – and friends or neighbours (Winnicott, 1964). Thus, we can infer that both for the feminine caregiver and for the person with a disability it is extremely hard to play a "social role" (Lepri, 2011, 2020) because they are stuck in a "mono-identity": a woman only identifies with the role of feminine caregiver, while the disabled child only identifies with the role of son/daughter for a lifetime (Isa, Ishak *et al.*, 2016).

Another significant point to highlight concerns the dimension of "rest": in Family A, despite the fact that the caregiver seems to have a lot of "free" time (no job, no social relationships, no leisure activities), she does not manage to rest for an adequate number of hours (only five a day).

We can thereby summarise that care-time dilation tends to decrease the well-being dimensions of the caregiver and invalidate her state of health. Her physical, mental and social

well-being is compromised by the excessive burden of care that restricts her set of capabilities (Sen, 2005). In other words, being feminine caregiver in Palestine brings to a capabilities deprivation that hinders women's empowerment both at home and in the society.

Conclusion

The ER provided a valuable approach both to foster knowledge and raising-awareness on the issue of disability and to promote self-awareness and empowerment of women involved in the research. As identified by the researchers, the feminine caregivers affirmed that their self-fulfilment is hampered by familiar, social, cultural and political barriers. The possibility to play an active role at home and in the community is the fundamental factor to reach a physical, mental and social well-being. As a matter of fact, a few brief remarks can be done embracing an inclusive and human rights perspective, by identifying some possible family, social, cultural and political changes towards the women's well-being.

Considering the barriers to well-being, we noticed that the issue of disability is barely mentioned by the feminine caregivers. This leads us to state that the presence of a person with a disability in the family is not considered an obstacle itself, but the real obstacle is the others' twisted perception of that condition. Actually, what women suffer is the social stigma – perpetrated by the family and the community – that affects both people with disabilities and their caregivers (Gardou, 2010; Hunt, 1966). The main problem is the lack of acceptance of the disable relative even within the family. This brings us to infer that the women – one of the most vulnerable groups in Palestine – realised that disability is not the real impediment itself, but it is socially produced and the real barriers are contextual (Oliver, 1996).

The data of the economic vulnerability of the familiar context due to the presence of a person with disability demonstrates, in fact, the lack of adequate and accessible public services, even in response of basic needs: education and health-care are significantly more expensive for a person with disability. This probably develops from a lack of sensitivity of policy makers that do not take into consideration the issue of disability when allocating public resources. If people with disabilities truly had the same social and civil rights of everyone else, they would have equal opportunities to access to mainstreaming services (Cinotti, Righini, 2018).

Moreover, accessible social services could be a response to the disabled people's need of socialization, education and development outside the family context. This would allow to build new relationships with people who are not the caregivers. At the same time, this possibility would guarantee a different use of the caregiver's time. Indeed, the hours dedicated to passive care could be spent in a more productive and satisfying way, both for people with disability and their caregivers.

Another possibility to lighten the burden of care is the involvement of fathers – or other relatives – in the education and the care-taking of the disabled child. Increasing the engagement of masculine relatives would contribute to develop a wider acceptance of disability and, consequently, an acquired knowledge and raised awareness. This might be a keystone of a cultural change for two reason: firstly, in the "disability history" the family has been the driving force behind social, cultural and political improvements in the inclusive direction (Pavone, 2014; Reynolds, 1976); secondly, it is plausible that, in the Palestinian patriarchal society, the possibility of a bottom-up change would be more effective if supported also by men, hand in hand with women.

All these factors are strongly integrated and interrelated and might positively contribute to widen the dimensions of well-being, towards the *infinite possibilities* of a better quality of life for people with disabilities and their caregivers (Caldin, 2016).

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