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**Quality of Life among Caregivers of Children with
Disabilities in the Gaza Strip**

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**Quality of Life among Caregivers of Children with
Disabilities in the Gaza Strip**

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Thesis Approval

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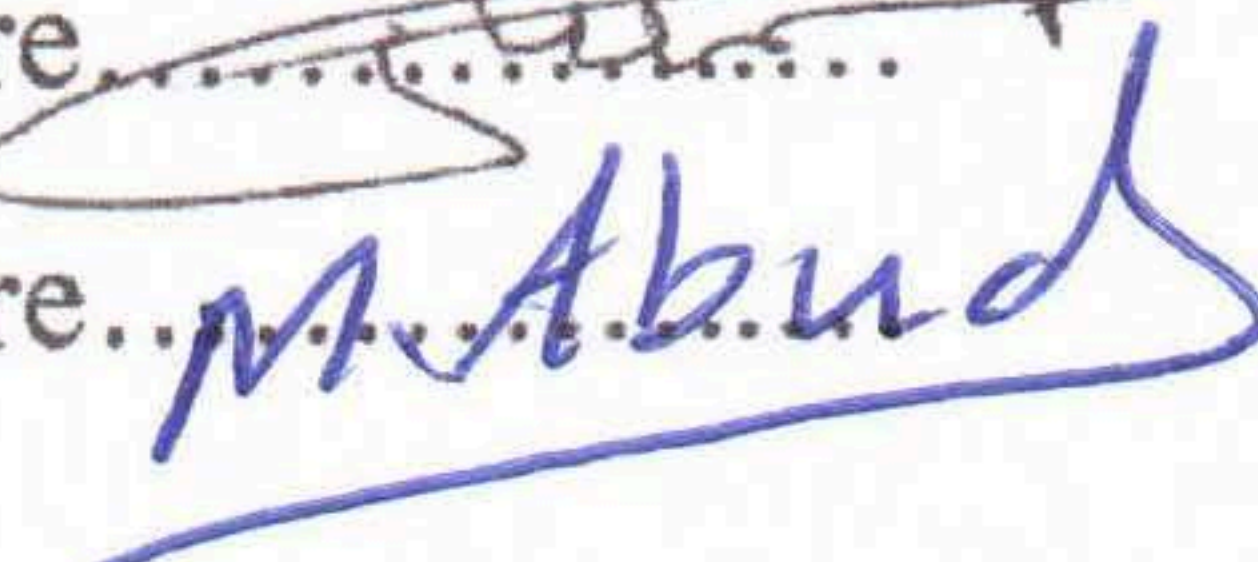
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Dedication

Dedicated to my father and mother who suffered from my stubbornness and did nothing but loving and supporting me.

To my Abdullah and Akram who suffered from my absence and less care and only waited until I am available.

To my Mohammed who suffered from my continuous stress and deadly ambition and he only took my hand and kept me patient.

To my sisters who suffered from continuous calls for emergency help and they did nothing but left everything back and ran to me.

To my lovely friends who suffered from my complaints and wailings and they only deeply heard me and filled me with energy.

To every mother who lived with an angel and suffered silently in shadow with no complaint and no one to help.

This effort is dedicated to those surrounding treasures.

Mariam A. Mohanna

Declaration

I certify that this thesis submitted for the degree of master is the result of my own research, except where otherwise acknowledged, and that this thesis or any of its parts has not been submitted for a higher degree to any other university or institution.

Signed:

Mariam A. Mohanna

Date: 11/1/2020

Acknowledgment

Dear respectful teacher, I thank you deeply for your continuous inspiration to do my best, you helped me strive for goals, you gave me guidance, discipline, even friendship, everything in one person; who is Dr. Bassam Abu Hamad. I am so grateful to my precious teachers; Dr. Yehia Abed and Dr. Khitam Abu Hamad because they taught me how and where to look not just taught me what to see.

Many thanks go to the experts who helped me in reviewing and revising the questionnaire and the key informants who gave me from their time and energy.

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Deep thanks to all caregivers who participated in the study because without them this thesis could not be accomplished.

With respect,

Mariam A. Mohanna

Abstract

Background Caregivers of children with disabilities experience a stressful life with many overwhelming challenges. This study assesses the quality of life of caregivers and highlights the burden of disability they shoulder and who supports them.

Methods This study followed a mixed-method cross-sectional approach. The quantitative component was administered on a randomly selected 400 caregivers of children with disabilities interviewed at the household level, with a response rate of 99%. Qualitative data collected through 11 key informant interviews, 6 in-depth individual interviews and 7 focus group discussions with parents of children with disabilities. Quantitative data were analyzed using the SPSS software and the qualitative data were analyzed using the open coding thematic technique. Reliability test was very high.

Findings Mostly mothers are the caregivers of children with disability (93%) and in more than 30% of the visited households providing care for more than one child with disability. Interviewed caregivers mostly belonged to poor, large size families and are mostly unemployed. The study points out that the overall caregivers' wellbeing score was 58%, 20% less than the wellbeing of the general population of the Gaza Strip. Similarly, the overall caregivers' Parental Stress was reported at 55.2% with parental distress domain eliciting the lowest scores (52.4%).

Although there are many difficulties facing caregivers of children with disabilities, the financial burden was the mostly prominent one that caregivers were challenged within securing medical services (83%), education (41.8%) and recreational activities (38.4%). Transportation and adaptation of public places were also major challenges that keep caregivers and their children home-bound.

Support provided to families is mostly provided through charity lenses, mainly from social assistant programs that are not adequately disability sensitive. Caregivers received little education and counseling on how to deal with their children. Most of the support provided to children with disability was provided by close family members (above 70%), while other people in the community like taxi drivers, salesmen at shops, people at religious or recreational places were showing less support. Sadly, only nearly half of caregivers felt that doctors, nurses and other health providers are supportive. However, even those who are theoretically supportive within and outside the family are not providing actual help and as the circle widens support decreases.

Regarding forgone opportunities, 75.25% had difficulties in securing recreational activities and leisure time and also forgone opportunities for socialization, attending social events and mixing with other people challenges as well as employment. With regard to the time use among caregivers, it was found that caregiving took a lot of time leaving much less time for rest, sleep and leisure activities, as the meantime for these combined was 3.7 hours daily and this affected their level of stress and wellbeing score ($r = 0.324, 0.260, p\text{-value} = 0.001$). The previous results were similar to qualitative results.

Moreover, inferential statistics showed that having an older child, living in a poor, extended and large size family and having more than one child with disability are being associated with lower wellbeing scores and a higher level of stress with statistically significant differences in comparison with counterparts. Strangely, the type of disability and gender of the child with disability did not show differences in the level of wellbeing.,

Conclusion Caregivers with children with disabilities need to be targeted and supported through psychosocial programs, providing counseling and information, respite care and also financially supported. There is a need to positively change services providers and the community members attitudes about disability and also modifying the package of services to be more disability sensitive services.

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List of Abbreviations

ADL	Activities of Daily Living
ASD	Autism Spectrum Disorder
CBR	Community-Based Rehabilitation
CP	Cerebral Palsy
CWDs	Children with Disabilities
DC	Difficult Child
FGDs	Focused Group Discussions
GS	Gaza Strip
HH	Household
ID	Intellectual Disability
IDI	In-depth individual interviews
KII	Key Informant Interviews
LS	Life Satisfaction
MOE	Ministry of Education
MOH	Ministry of Health
MOSD	Ministry of Social Development
NGOs	Nongovernmental Organizations
OECD	The Organisation for Economic Co-operation and Development
PA	Palestinian Authority
PCBS	Palestinian Central Bureau of Statistics
P-CDI	Parent-Child dysfunctional interaction
PD	Parental Distress
PIMD	Profound Intellectual and Multiple disabilities
PNCTP	Palestinian National Cash Transfer Program
PSI	Parental Stress Index
PWD	People with Disability
QoL	Quality of Life
UN	United Nations
UNICEF	UN Children's Emergency Fund
UNRWA	United Nations Relief and Works Agency for Palestine Refugees in the Near East
WHO	World Health Organization