

Breakout Session 1: Mental Health and Wellbeing

17th March 2022



Breakout Session 1:

Mental Health & Well-being

Chair: Liz Sayce	
Diana Setiyawati & Annabella Osei-Tutu	The impact of the Covid-19 pandemic on mental health care for people with psychosocial disabilities in Indonesia and Ghana
Richard Brunner	“Welcome to my world”: exploring the experiences of people with pre-existing mental distress during COVID-19 (UK)
Joanne Neille	“I’m not ok, we are not ok”: The experiences of disabled people in rural South Africa during the COVID-19 pandemic.
Zeynep ilkkursun	COVID-19 & Disability Study: Syrian Refugees with Disabilities in Turkey
	Q&A

Diana Setiyawati & Annabella Osei-Tutu
Universitas Gadjah Mada & University of Ghana

The impact of the Covid-19 pandemic on mental health care for people with psychosocial disabilities in Indonesia and Ghana



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The impact of the COVID-19 pandemic on mental health care for people with psychosocial disabilities in Ghana and Indonesia



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Aims and methods

Aim: To understand the impact of COVID-19 on people with psychosocial disabilities in Ghana and Indonesia and inform guidelines for inclusive recovery

Methods:

- Peer researchers with lived experience of psychosocial disabilities trained to work with the research teams throughout the research process
- Interviews on-line/face-to-face conducted with people with lived experience of mental illness, caregivers and stakeholders to explore the impact of COVID-19 and sources of support
- Interviews analysed thematically through participatory workshops
- In this presentation we are focusing on the **impact on availability and quality of mental health care**

Field sites



Mental health services in Indonesia and Ghana

- **Funding:** public funding (ring-fenced), international development partners' support, NGOs. Low priority - funding for mental health ~0.1% of health budget.
- **Access/availability/affordability:** Limited access; insufficient human resources for mental health; high cost of treatment (esp. psychotropic medicines) and care.
- **Human right concerns:** Both countries have ratified the UN CRPD and established laws and policies which aim to reduce human rights abuses against people with mental illness, including collaboration with traditional and faith healers, reform of mental health legislation and the 'free *pasung*' programme (Indonesia).
- **Mental health advocacy:** In both countries, civil society organizations/NGOs play a key role in training people with lived experience of mental illness in peer support, advocacy, and disability rights.

Daily new confirmed COVID-19 cases

7-day rolling average. Due to limited testing, the number of confirmed cases is lower than the true number of infections.



Ghana

- Lower level of community infection
- Fewer restrictions
- Scepticism around whether the virus was real
- Very few people vaccinated (15.4%)
- Masks and hand sanitizer expensive
- Rising cost of living e.g., food, transport



Indonesia

- High level of community infection, sickness and mortality
- Prolonged local lockdown
- Pressure on health services
- Widespread fear of infection
- Team members experienced bereavement due to COVID
- People with SMI more vulnerable to COVID-19
- Some researchers also living with vulnerable family members



Results

- Resources for mental health care, including budgets, facilities and staff, were diverted to COVID-related interventions.

“Mental health was already struggling financially and then COVID made it worse [...] we needed to [...] find personal protective equipment that was needed by staff and clients to ensure we were able to operate as a hospital.” (Stakeholder, Ghana 1-GH)

“... in the end there are many medicines whose procurement is a bit delayed because we prioritized Covid first. So, in the end, for several months, the medicine was depleted because the funds for the drug were diverted. So it's not a priority, there are other priorities. So we have to change the medicine. If not, it's a pity that the patient has to buy medicine outside. If we prescribe it outside, it's a patent medicine, the patent that isn't generic, so the price is expensive, that's also a problem.” (Stakeholder, Indonesia)

- Participants found it harder to access treatment, whilst experiencing a deterioration in their mental health.

“I was finding it difficult during the COVID time because before the medicine, like I said, I've been buying it at the pharmacy ... I'd been buying it at the hospital and the amount was less but during the COVID time I have to buy it at the [private] pharmacy and it's very expensive” (Person living with psychosocial disability Ghana. PO3-GH)

“I can't go there [to the clinic] ...can't go out of the house and village cadres helped. I have a story like this, I'm confused, yes, how to go onlineluckily the village cadre helped me” (Person living with psychosocial disability Indonesia. P2-IND)

- Decreased availability of mental health services increased reliance on families and traditional/faith healers and harmful practices such as physical restraint.

“[During the lockdown], I think about five patients of ours got relapse because we were not able to go to the house to take care of them” (Stakeholder 2- GH)

“During the pandemic, there was an increase in people being put in pasung again” (Stakeholder 2-IND)

- Innovations included telephone helplines, online support and a shift to home visits. However, these were not equally accessible, particularly to the poorest.

“Now the positive thing is that now people are okay with the tele consultation. [...] it has come to stay. All the contactless things in a way helps speed up work and makes things more convenience for us and also for the clients.”

(Stakeholder 3- GH)

“Previously, I still see the doctor once a month. Then this pandemic... So it's like I'm scared, right? In the end, I actually came once a month just to take medicine, and brief consultation because the hospital was also limiting the time [for appointments]. And in the end, fortunately, my doctor can use Zoom too. So he is willing to spend time for the consultation, like psychotherapy via Zoom. So I didn't meet him at the hospital. I used Zoom, which is twice a week, once every two weeks. [...] So I only went to the hospital to get medicine.”

(Person with psychosocial disability, Indonesia)

Conclusion

- The impact of COVID-19 can threaten recent advances in mental health care in resource-deprived settings but also presents opportunities for innovation, such as online and home-based support.
- However there is unequal access to such support, for example limited internet access, literacy, rural areas etc.
- Need to consider how such innovations can be more inclusive and reach the most marginalised.

Richard Brunner
University of Glasgow

“Welcome to my world”: exploring the experiences
of people with pre-existing mental distress during
COVID-19 (UK)



University
of Glasgow

“Welcome to my world”: exploring the experiences of people with pre-existing mental distress during COVID-19

University of Glasgow: Richard Brunner, Nicola Burns, Jane Cullingworth, Charlotte Pearson, Nick Watson, Philly Wiseman

London School of Hygiene & Tropical Medicine: Shaffa Hameed, Nathaniel Scherer, Tom Shakespeare

UKRI funded: Jun 2020 – Jun 2021

**WORLD
CHANGING
GLASGOW**

THE SUNDAY TIMES
GOOD
UNIVERSITY
GUIDE
2018
SCOTTISH
UNIVERSITY
OF THE YEAR

Aims of overall study

To produce evidence as to how disabled people in England and Scotland are experiencing the COVID-19 pandemic

To recommend short and medium term response measures, including what disabled people identify might help them

Disabled people? A range of impairment groups – including people with enduring mental distress (PWMD)

Methodology

- Qualitative longitudinal sociological study
- Semi-structured, in-depth interviews with disabled people and disabled people's organisations (Zoom/phone/email)
- Two rounds of interviews: Jun-Aug 2020 (UK lockdown 1) and Jan-Mar 2021 (UK lockdown 2)
- **#20 PWMD round one, #16 PWMD round two**
- Most aged 18-64, identifying as female, living alone (2 identifying as BAME, 1 as LGBTQ+)
- Thematic analysis using Nvivo

England / Scotland context for PWMD

- **Social and economic gradient** - people with enduring mental distress (MD) in UK are **more likely to be in poverty, out of work, poor housing, have other underlying conditions** (Wilkinson & Pickett, 2009) - a well-established gradient (Marmot et al, 2021).
- **UK austerity programme (2010-)**
 - reduction in MH support services, with a disproportionate impact on people living in poverty (Cummins, 2018).
 - restructuring of welfare system: Work Capability Assessments & greater surveillance if seeking state support – **steepening the gradient** (Mills, 2018; Wright, 2020).
- **UK discourses of ‘recovery’, self-help, resilience** have worked to individualise explanations of distress causes - and how people navigate their distress (Rose, 2019).

A. Isolation tended to intensify pre-existing MD

Round 1: Lockdown constraints, Covid anxieties & lack of groups and friends meant MD typically intensified or returned:

'...I'm back at square one feeling agoraphobic & anxious all over, going back again.' (Hannah S21)

'when [MH user group] stopped ... I went back into the black hole that I'd been out of for some considerable time.' (Lily S09)

Round 2: For some, MD had continued to worsen: *'all the demons I had fought to overcome, like my anxiety, my agoraphobia ... COVID has allowed me to go right back into those behaviours ...'* (Hannah 2S21)

Secure income could make a difference e.g. furlough: *'that's a big help financially and just knowing that job security. It's probably why it helps my mental health, it keeps me calm...'* (Helen 2S32)

B. People actively self-managed their MD; BUT Covid revealed limits

Round 1:

Motivation: *'...with COVID-19, my anxiety has been flaring up... I've been given CBT... It is helping but at times it's the motivation ...'* (Anne S34)

Harm reduction: *'I can sometimes just burst out crying ... just the stress of it all... I'm a massive self-harmer. I haven't done it in 2 years so the last thing I want to do is go back to that so if crying is what it takes, then crying is what it has to be ... It's better than self-harming.'* (Hannah S21)

Round 2:

Self-medication: *'I've had to take [Lorazepam] regularly, because of nightmares, and different things, just to get me ... to sleep. Hopefully, that will sort itself out once this is over.'* (Adam 2S15)

Breaking lockdown rules: *'... because of my MH ... even though we weren't supposed to do it, I have gone for a walk twice a week with a friend ... without that, I don't actually think I'd be alive.'* (Megan S10)

C. COVID-19 indicates how MH services can better support people with enduring MD

Round one: COVID-19 sometimes demonstrated **the fundamental value of MH services** to people: *'If it hadn't been for the help of the [name] community MH team I wouldn't be here. It was that bad...'* (Lily 2S09)

Round two: COVID-19 revealed how **service ethos** really matters to people, sometimes adding choice and control, beyond the statutory minimum/crisis intervention, into supporting wellbeing:

'They phoned us up and asked ... what do you like doing? Do you like colouring-in? I thought, colouring-in, mindfully, I fancy that. And they sent me a box out, right, with a colouring-in book, wordsearch... stress ball ... It was very useful. Somebody took an initiative and sent that out ... we were treated with respect... it was so nice of them. It wasn't something they usually do.' (Lily 2S09)

D. People feared for the future of their pre-existing MH support

UK Government COVID-19 MH campaigns focused on those with new or emerging MH issues, reinforcing marginalisation of those with enduring mental distress.

‘when we say to somebody, “go for a walk to clear your head, it’ll make you feel better”, I think by the time somebody is feeling really bad that advice is too late.’ (Arthur S12)

‘where’s the help for us?’ ... ‘it was a grave error to put so much money into mental health and completely ignore mental illness.’ (Megan 2S10)

‘Like mental health has been an issue for fucking decades and nothing’s been done about it. But then COVID-19 comes and locks rich people and everybody in their houses and then all of a sudden mental health is a big issue.’ (Hannah 2S21)

Conclusions – Covid + Covid lockdowns:

- Compounded longstanding inequalities faced by people with MD
- Confirmed that mental distress is socially situated and responsive to our environments
- Demonstrated limits to 'self-help' and resilience concepts
- Demonstrated how PWMD value statutory services (also user-led groups) – and offers new evidence to statutory services about how to take a more holistic and preventative role
- PWMD are angry that they have been marginalised again, with no acknowledgement of enduring MD in UK Government campaigns
- UK austerity experiences mean there is a fear of MH service retrenchment due to the need to serve 'new' PWMD.



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*'Well I feel, welcome to my world, that I
have always been isolated...'*
(Belinda, 35 years' experience of a
bipolar diagnosis).

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@UofGlasgow

Joanne Neille

University of the Witwatersrand

“I’m not ok, we are not ok”: The experiences of disabled people in rural South Africa during the COVID-19 pandemic.



“I’m not ok, we are not ok”: The experiences of disabled people in rural South Africa during the COVID-19 pandemic.

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Background to study



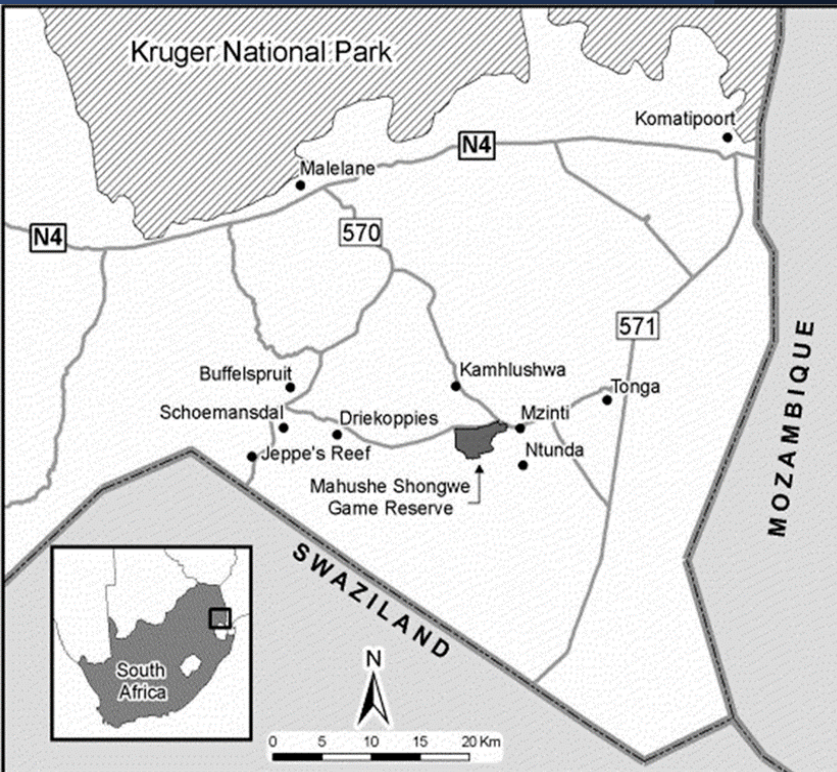
- Diverse country at the tip of Africa
- South Africa continues to battle the after-effects of apartheid which has resulted in it being described as one of the most unequal countries in the world
- 7.7% of the population are documented as disabled (Statistics South Africa, 2016), the majority of whom live in poverty-stricken areas
- Proactive response to slowing the spread of the COVID-19 virus, yet this created significant challenges for disabled people
- Although the response was effective, it magnified the social, economic and educational divides within communities



Methodology

Setting

- Nkomazi East Municipality within the Mpumalanga Province, between the borders of Swaziland and Mozambique
- Considered to be one of South Africa's 'poverty pockets'
- Sustained relationship with the community for over 20 years



Design

- Qualitative study underpinned by naturalistic inquiry
- Unstructured interviews were conducted in English with two key informants.
- Interviews with disabled people and their family members were conducted by a local SiSwati speaking research mediator
- Eight semi-structured interviews were conducted in Siswati with people with disabilities.
- Five family members/caregivers of disabled people were also interviewed.
- All data were transcribed and translated into English, then analysed using inductive thematic analysis (Braun & Clarke, 2006).

Participants

Key Informants	Participants with Disabilities	Family members/caregivers of persons with disabilities
1 x female community-based rehabilitation worker Disabled person confined to a wheelchair as a consequence of polio	8 disabled people Age range from 21 – 63 years 5 male; 3 female 1 participant with communication impairment; 2 participants with sensory (visual) impairments, 5 participants with physical impairments	5 family members/caregivers of people with disabilities Age range 32-65 years All caregivers were female Three were caring for family members with multiple disabilities (physical, communicative and intellectual impairment), and 2 were caring for people with physical impairments
1 x female occupational therapy assistant		

Findings



Decreased access to healthcare and social support

“Since COVID, it is difficult to get assistance. Especially places like the hospital. Even to get to our councillors to ask for help with food is too difficult. That’s why we end on being discouraged and give up.” Participant 1, 36-year-old male with physical impairment

“There was a certain lady from the group of home base care, used to come and bring my treatment once a month but when lockdown started, she disappeared.” Participant 3, 43-year-old female with physical impairment

“It was very difficult to get help at the hospital. The security were assessing and questioning everyone in the main gate. For disabled people, they were just turning us away.” Participant 7, 52-year-old female with physical impairment

“Sometimes we will return home without help. People at the main gate were refusing for disabled people to enter.” Participant 8, 41-year-old female with communication impairment

“At the clinic it is worse now because we are not allowed to enter inside. We have to wait outside the main gate, just sitting in the sun because only five people can enter at a time.” Participant 4, 63-year-old male with visual impairment.

Increased sense of isolation and discrimination

“I couldn’t even go outside, and the neighbours who used to help me were scared to see me now, scared in case I had the virus.” Participant 1, 36-year-old male with physical impairment

“My mother is the one who helps me, but she was in Johannesburg when they stopped travel between provinces, and she couldn’t get back here. It was very difficult for me because I had no-one and even the home-based care people stopped coming. Participant 2, 19-year-old male with visual impairment

“At home I was ok, but going outside the gate is difficult, because I’m not trained. I have to ask some guy to assist me. Now with the virus, people are scared to help us.” Participant 4, 63-year-old male with visual impairment.

“There was nobody. It was just me, my husband and our kids in the house. Nobody to help us with anything and no food to eat. It was very, very bad.” Caregiver 1, 32-year-old female and wife of a husband with a physical impairment

Challenges with PPEs and social distancing

“I used to put mask to protect (name of granddaughter), even at night, because we were sharing one bed and I was afraid that I could infect her. But sho, it can be scary because sometimes she has difficulty breathing and the masks make it worse.” Caregiver 2, 65-year-old grandmother of 21-year-old granddaughter with cognitive, communicative and physical impairments

“Because we could not sell our fruits on the roads during lockdown I started making umcombathi (traditional beer) to make money but now I have a problem because the people who come here to buy are coughing and not wearing masks and we don’t have money for sanitiser.” Caregiver 3, 33-year-old female and sister to 28-year-old female with cognitive, communicative and physical impairments

“The biggest challenge is social distancing because like me, I need someone to help me with dressing and bathing, so it is not easy to maintain social distancing. Also, we do not always have money for masks and soap.” Participant 3, 43-year-old female with physical impairment

Increased food and financial insecurity

“We were having a small business trying to sell vegetables on the road, but then it stopped. It was not easy to get food to sell, and with lockdown people were not walking on the road, coming to buy from us.” Participant 8, 41-year-old male with physical disability

“We were told that we don’t qualify to receive food parcels because my wife is receiving disability grant.” Caregiver 3, 33-year-old female and sister to 28-year-old female with cognitive, communicative and physical impairments

“We could not even buy jersey or warm clothes for our children, and it was very cold. There was nothing that we can do because there was no money.” Caregiver 1, 32-year-old female and wife of a husband with a physical impairment

“Yoh! There is no money, everybody is crying. Even if you go to your neighbour to ask for mealie meal, you will see that even your neighbour has nothing.” Caregiver 2, 65-year-old grandmother of 21-year-old granddaughter with cognitive, communicative and physical impairments

Conclusions



Conclusions

- Experiences of poverty, isolation, discrimination and decreased access were magnified for disabled people living in rural South Africa during the COVID-19 pandemic
- COVID-19 allowed for further marginalisation and erosion of disabled people's rights
- Informal triage systems allowed for personal biases to emerge with detrimental effects of both access and
- Findings highlight the need for increased awareness of disability, the fundamental needs of disabled people, and the social, financial and mental health implications that the pandemic and societal response had on disabled people
- Additionally findings highlight the need for social support, and policy reform, with a specific focus on basic human rights including access to information, healthcare, and nutrition.

Zeynep Ilkkursun

**COVID-19 & Disability Study: Syrian Refugees
with Disabilities in Turkey**

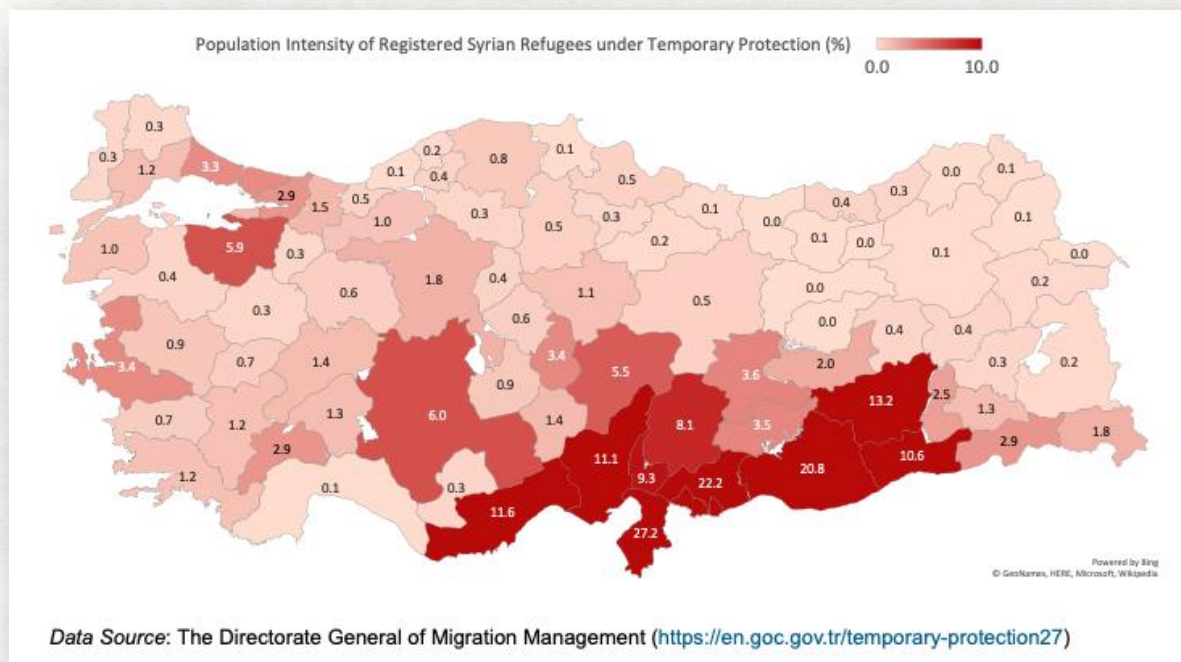
COVID-19 & DISABILITY STUDY: EXPERIENCES AMONG SYRIAN REFUGEES

- 17.03.2022

Ceren Acarturk
Gulsah Kurt
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In partnership with the International Centre for Evidence in Disability, LSHTM

SYRIAN REFUGEES IN TURKEY



Over 5 million people have fled Syria since 2011, seeking safety in Lebanon, Turkey, Jordan and beyond. Millions more are displaced inside Syria and, as war continues, hope is fading fast.

-UNHCR

Registered Syrian Refugees

3,750,462

Last updated 10 Mar 2022

MENTAL HEALTH OF SYRIAN REFUGEES – PRE-PANDEMIC

Common mental problems in Syrian refugees

- 14-44% Depression
- 11-83% PTSD
- 13-30% Anxiety

(Acarturk et al., 2018; Gammouh, et al.,. 2015; Naja, et al., 2016)

Common mental problems in Syrian refugees in Sultanbeyli

- 455 males (56%) and 313 females (36%) reported experiencing or witnessing others experience a potentially traumatic event
- The prevalence of symptoms of PTSD, depression, and anxiety was 19.6%, 36.1% and 34.7%, respectively
- Almost half of our participants (46.9%) were experiencing symptoms of at least one mental disorder

(Acarturk et al., 2021)

THE ASSOCIATION FOR SOLIDARITY WITH ASYLUM SEEKERS AND MIGRANTS (SGDD-ASAM) ESTIMATES THAT APPROXIMATELY 450,000 OF THE SYRIAN REFUGEES IN TURKEY LIVE WITH VARIOUS DISABILITIES.

“Being a refugee is hard.

Being a disabled refugee is
a whole other thing!”

- Khadija syrian refugee

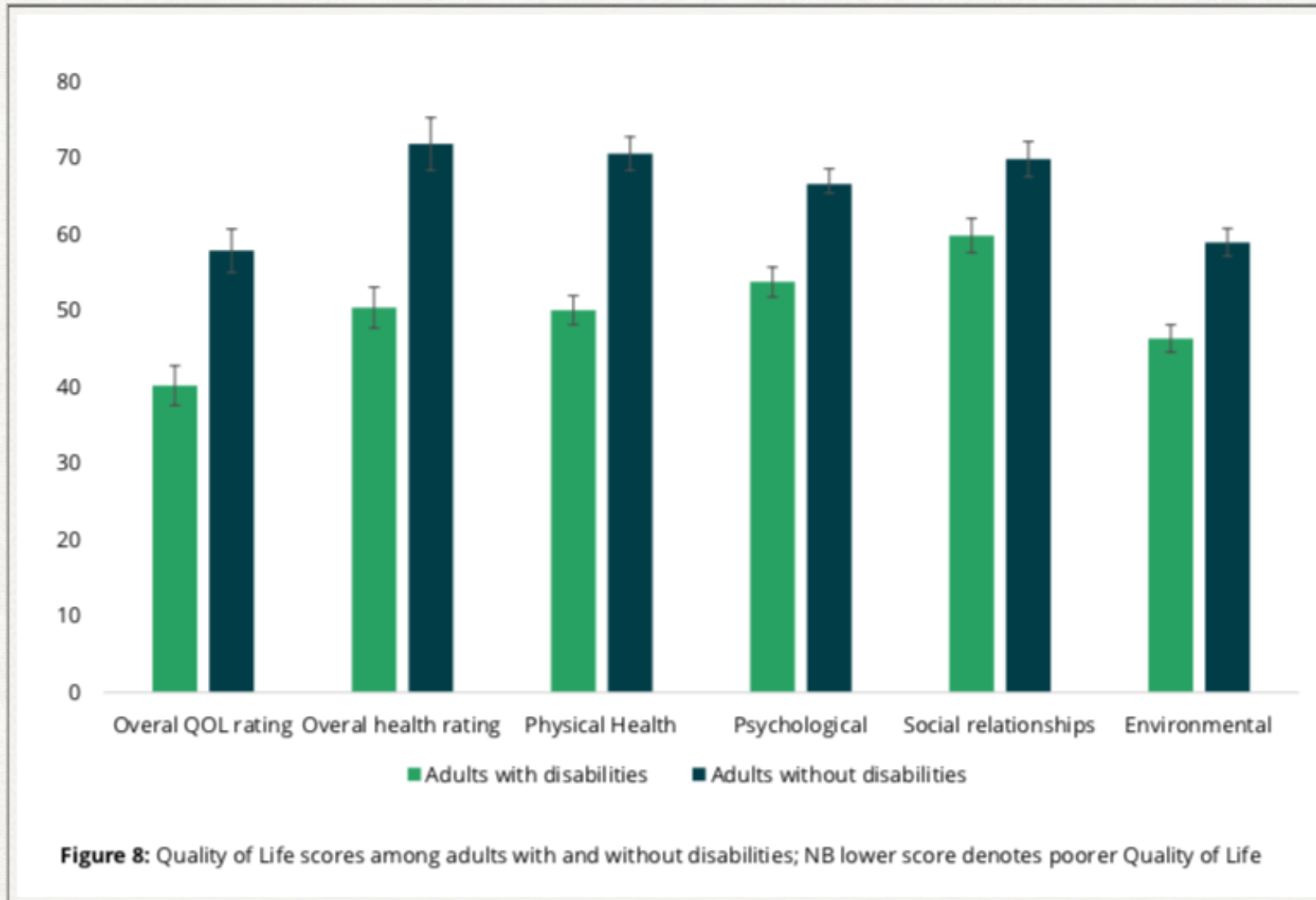


SYRIAN REFUGEES WITH DISABILITY

- PRE-PANDEMIC

- Key findings:

- 3,084 people participated in the survey (response rate = 77%)
- All age disability prevalence of **25.8%**
- Disability prevalence **increased with age** and was **higher for women** compared to men
 - Prevalence was 50.6% among adults aged 50+
- Prevalence of mental health symptoms in children aged 7-17 was **29.5%**
 - Coping mechanisms include religion and family
- **62% of households** had at least one household member with a disability
 - Households including a person with a disability had a higher dependency ratio and a lower proportion of adults in employment



COVID-19 & DISABILITY STUDY

- **Aim:** to explore the **experiences of people with disabilities** in different LMICs **during the COVID-19 pandemic** and **identify possible strategies** to better promote the inclusion of people with disabilities in response activities
- Funded by IDS, part of the Covid Collective
- Partnership between Koc University and LSHTM
- **Method:**
 - Qualitative interviews with Syrian refugees who have disabilities, interviewed twice
 - Key Informant interviews with stakeholders, professionals working with disabled refugees
 - Fieldwork currently underway

EMERGING THEMES FROM THE FIELD

- Information on COVID-19
- The impact of COVID-19
- The coping strategies for the

impact of COVID-19

- Suggestions

...apart from *vaccination issues*, let's say you have a chronic illness related to health. *Not being able to access health for economic reasons* has become a very serious problem. The *language barrier* is added to this, of course...Apart from that, for example, there are people with disabilities who want to apply special nutrition programs due to their special diseases. [...] *Prices are incredibly high.*

- Key informant working with disabled refugees

INFORMATION ON COVID-19

- The knowledge on the symptoms
- Worry related with COVID-19
- The personal risk assessment regarding getting infected
- The protection measures
- The vaccination

Incomplete knowledge

R: *I don't know anything about corona or the symptoms or masks and lockdowns, I don't even go out except to pray and even a lot of time I don't go out for Isha prayer because am afraid I would slip*

I: So, you don't know any symptom or any precaution?

R: *No, they just called a couple of weeks ago and told me to get vaccine and I did.*

- Syrian refugee with a physical disability, female, 62

Personal risk assessment

R: *I would tell my kids...I'm the most vulnerable between you.*

- Syrian refugee with a physical disability, female, 49

THE IMPACT OF COVID-19

- Financial situation

- Work/Employment

- The impact of the pandemic on school

- Accessing general health services/needs

- No change in receiving services

- Difficulty in getting appointments for health services (doctor, treatment etc.)

- Unable to buy medications/drugs due to increased price

- Accessing disability related health services

- Receiving assistance (from family/friends, organizations, government etc.)

- Ability to get food and other essentials

- Social life

- The psychological impact of COVID-19

Interruption to work and financial assistance

I was working before COVID-19. I used to make around 2200 TL (185,05 GBP). I was working 7 hours a day...my work changed now I work as a truck driver...I stopped working because I was in self isolation...I had to be in debt. There was no one helping me. I didn't get a compensation even though I had insurance and work permit.

- Syrian refugee with a physical disability, male, 42

I was working for 4-5 hours a day and by the salary we were get our food from markets [...] the financial resources decreased which affected the amount of food we used to buy for the house. So yes, it affected us a little bit, especially when Red Crescent the financial assistance stopped as well.

- Syrian refugee with physical disability, male, 22

THE IMPACT OF COVID-19

- Financial situation

- Work/Employment

- The impact of the pandemic on school

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- Accessing disability related health services

- Receiving assistance (from family/friends, organizations, government etc.)

- Ability to get food and other essentials

- Social life

- The psychological impact of COVID-19

Difficulties seeking and reaching services

I used to go to the hospital every Friday to take the needle for my back pain and that's it. But I did not use any tools like a wheelchair... During the pandemic the accessibility to this needle was harder and I could not get it when the pandemic started. I started to take it again 5 days ago only...I was not able to go to the hospital, we don't have a car so it was hard for me to go to the hospital.

- Syrian refugee with physical disability, male, 22

Inability to purchase food and other essentials

He'd eat vegetables, he'd eat everything. Not dry bread. One kilogram of apples is 10 TL, one kilogram of oranges is 10 TL, how can I afford this, my son?

- Syrian refugee with physical disability, male, 49

THE COPING STRATEGIES FOR THE IMPACT OF COVID-19

- Religion
- Working
- Choosing not to receive/get treatment/services/essentials
- Decreasing the amount/quality of essentials/services
- Receiving assistance

Religion as a way to cope

We are alive, thank God. We don't ask for money from anyone nor tell anyone.

- Syrian refugee with physical disability, male, 49

Decreasing the amount/quality of essentials/services

R: We get medium quality things, not the best quality.

I: Oh, so you changed the type of food itself?

R: Yes, yes. For example, we don't take the best of the best, we take the average ones. Like they say in the common language.

- Syrian refugee with a physical disability, female, 40

SUGGESTIONS

INCREASING THE ACCESS TO INFORMATION

PRIORITIZATION OF IMPAIRMENT-RELATED HEALTH SERVICES,

AND FINANCIAL ASSISTANCE FOR SYRIAN REFUGEES WITH
DISABILITIES

COVID-19 & DISABILITY STUDY: SYRIAN REFUGEES WITH DISABILITIES IN TURKEY

• 17.03.2022

THANK YOU FOR LISTENING!

Ceren Acarturk
Gulsah Kurt
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Supported by the International Centre for Evidence in Disability, LSHTM