

# Defining a life worth living, recovery and well-being from the perspective of people starting DBT

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## Overview

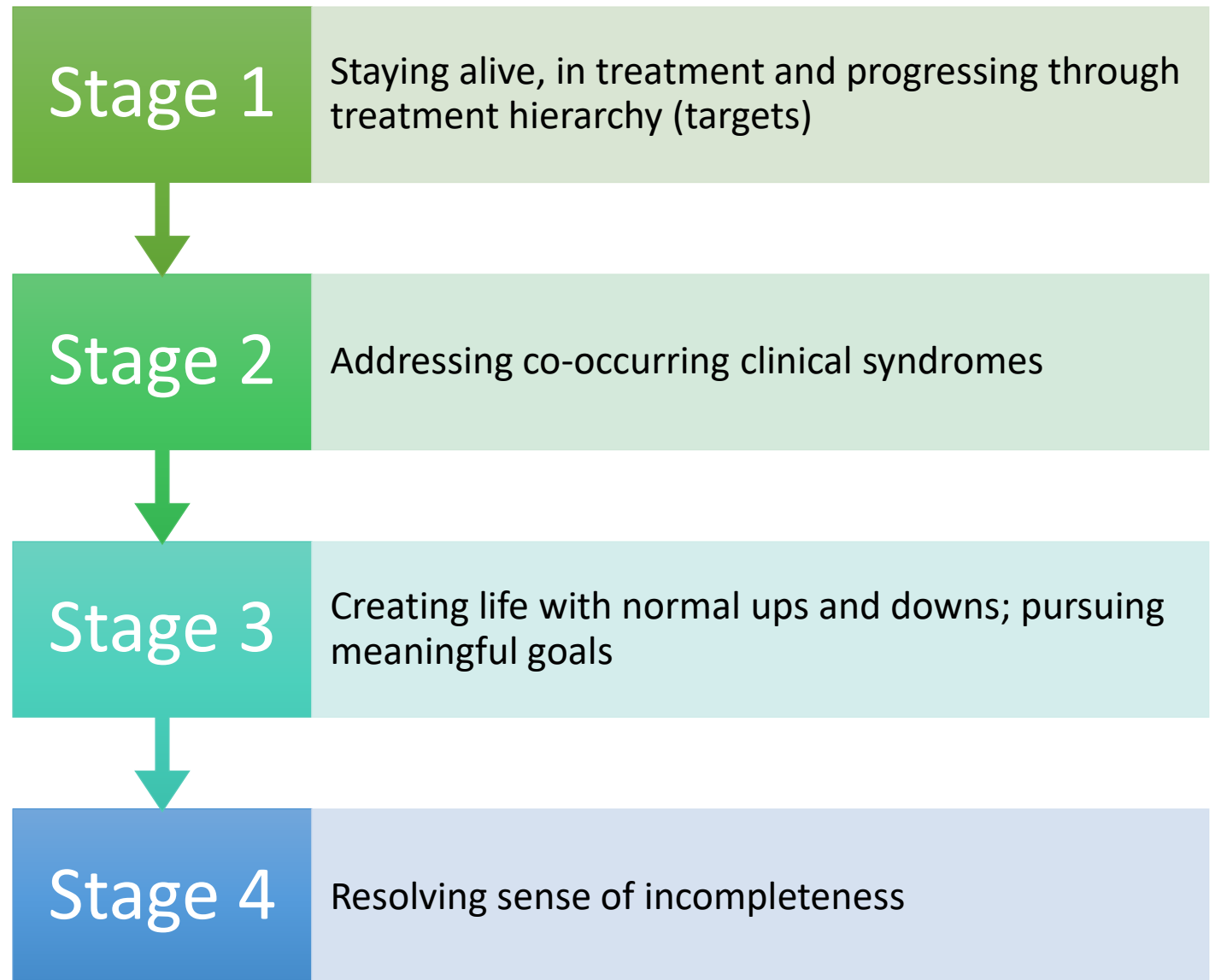
- Acknowledgements
- Background
- Overarching collaboration study
- Current study: Outpatient DBT Cohort
- Sample
- Preliminary findings
- Discussion
- Recommendations & Next Steps

# Acknowledging Professor Marsha Linehan and DBT



- Marsha Linehan, Professor of Psychology, Psychiatry and Behavioral Sciences at the University of Washington and Director of the Behavioral Research and Therapy Clinics
- Linehan retired in 2019.
  - Before and since then the treatment she developed, Dialectical Behaviour Therapy (DBT) has been adapted and modified to treat a number of clinical syndromes, at times co-occurring, that address changing patterns of behaviour
  - Addictions;
  - PTSD
  - Eating disorders;
  - Social anxiety disorder

DBT is  
characterized by  
four stages of  
treatment and  
targets therein  
(Linehan, 1993; 2015)







*life experienced as  
worth living (LWL)*

- Within the Dialectical Behavior Therapy (DBT) literature a *LWL* is formulated as the epitome of freedom from the chaos of borderline personality disorder (BPD).
- However, we do not know how those who have received DBT for BPD and associated suffering define the concept of LWL
  - What it means to have a LWL has not been operationally defined
  - There is no criteria or measurement or LWL definition
  - How can we know whether and when people attain a LWL?

Without an agreed-upon operational definition of LWL, those who complete DBT treatment may have unmet treatment expectations and needs

- In the absence of defining LWL, there is no framework to move beyond symptom counts, life satisfaction and indicators of social integration such as employment, which comprise much of the current status of the recovery literature
- It is also unknown to what extent those who complete DBT have a LWL, which is problematic if an LWL is what we promise at the outset of treatment

# ”Symptom remission” a usual standard

- In medical research including psychiatry research, a treatment is defined as effective when a person no longer has symptoms of the illness if evaluated by Randomized Controlled Trial (RCT).
  - However, no longer self-harming or meeting diagnostic criteria for BPD at the end of treatment does not necessarily mean that people are feeling or doing well.
  - This is an epistemological problem in medicine and research.



## Not criticisms of DBT

- or RCTs
- or becoming symptom-free

**It is a huge victory to stop self-harming and suicidal behaviour and to overcome a PD diagnosis**

**... and it is a huge amount of work to do an RCT (!)**

**What I am referring to are limitations of our ways of knowing based on the literature at the outset of our study**



# Syptom remission $\neq$ a life experienced as worth living

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THIS IS NOT JUST A PROBLEM FOR DBT. IT IS A PROBLEM FOR ANY EVIDENCE-BASED TREATMENT FOR PD THAT HAS SYMPTOM REMISSION AS A DEFINITION OF CLINICAL EFFECTIVENESS AND EFFICACY.



WHAT SHOULD WE DO IF SYMPTOM REMISSION IS WHAT DEFINES A TREATMENT AS EFFECTIVE, AND WE WANT TO UNDERSTAND WHAT IT MEANS TO HAVE LWL?

IS THERE MORE THAN LWL?

*“Make sure you know what you are measuring before you start measuring it”* - M. Wångby-Lundh, Lund, 2015



## LWL in relation to DBT

- In her treatment manuals (1993; 2015) Linehan discussed LWL as possibly happening in Stage 3 and 4 of DBT, which have not been fully manualized
- Marsha proposed that freedom from chaos and suffering were possible as was living with purpose and meaning
- She also proposed that a deeper sense of connectivity to others and the Universe (for those who are spiritual) was also possible



## LWL (and beyond?)

### **LWL comes into DBT during the commitment phase:**

- People in therapy are asked to give a commitment to stop self-harm and other self-damaging behaviours in return for the promise of a life that feels worth living by the end of treatment
  - It feels reasonable because a suicidal person probably cannot – in that moment – imagine life being “amazing.”
    - But what happens when people are not suicidal anymore?
    - Is the promise of a LWL enough?

# Current collaboration study

- A three-site collaboration study was conducted with the overall aim of defining a LWL by those with lived experience -VGFOUREG-979602
  - To include participation from individuals across the illness-to-wellness spectrum, we recruited participants from three different settings.
- The current study that I will share the results from an outpatient DBT cohort



# Inclusion criteria for participants beginning outpatient DBT

Severe and repetitive self-harming and life-threatening behaviour alongside:

i. Three or more diagnostic criteria of Borderline Personality Disorder: BPD

ii. Co-occurring PTSD may be present, but not necessary for inclusion

iii. Age between 18-65.

iv. Ability to give consent.

v. Ability to read and write in Swedish.



# Sample size and analyses



A TOTAL OF 9 PARTICIPANTS WERE  
RECRUITED



THIS NUMBER OF PARTICIPANTS WERE SUFFICIENT  
TO DEVELOP CLEARLY DEFINED THEMES WITHIN  
QUALITATIVE THEMATIC ANALYSIS (TA)

# The current sub-study focused on a cohort beginning standard outpatient DBT in 2020-2021



For this sub-study, nine individuals, all of whom were starting DBT, took part in semi-structured interviews on LWL and related topics.



Interviews were audio recorded and transcribed and translated from Swedish to English



# Thematic analysis (TA)



TA was conducted through the six phases outlined by Braun and Clarke



Analysis and interpretation of the data was conducted at the semantic level.



That is, we followed what participants said exactly rather than interpreting their interviews during the analysis of interview data

# Thematic analysis conducted by two coders independently (HG & SIL)

- Data were analysed by HG and SIL, whereby the entire dataset was coded and analysed twice
  - Nvivo 14 software was used to for analyses
  - Concordance between coders was strong
  - Main themes and subthemes were reviewed by co-authors; one of whom conducted interviews (KS) and one of whom is an expert in this area (LCK)

## Preliminary findings

- Four main themes and thirteen sub-themes were derived from thematic analyses describing participants' ideas and experience of LWL.





## **Main theme 1: LWL possible to hope for if hard to envision now**

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LWL feels far away and maybe unrealistic

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Hopes for and wants a LWL

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Can imagine future LWL in relation to specific close relationships

# Strengths & Limitations

- **Strengths & limitations of the study**
  - **Strength:** We collected our data during the pandemic with interviewers who continued working despite this. We are grateful to our collaborators and study participants
  - **Limitation:** It limits transferability that all participants identified as female and European / Swedish.
- **Strengths & limitations of thematic analysis (TA)**
  - **Strength:** In TA you are looking for recurring patterns in your data that come up enough for you to feel that you have identified commonalities (saturation)
  - **Limitation:** Unique and important individual responses are not reflected in the analysis

# Next steps



ANALYSIS OF LWL+ INTERVIEW DATA FROM AN INPATIENT DBT COHORT IS CURRENTLY UNDERWAY.



THE NEXT PAPER AIMS TO COMPARE THOSE COMMENCING TREATMENT IN INPATIENT AND OUTPATIENT SETTINGS.



# Completing project

- Paper on recovered cohort already published, which is what sparked collaboration with LCK
- Final papers from this project will be to compare perspectives of those with lived experience across the illness-to-wellness spectrum in relation to LWL definitions and experiences of flourishing, and to contrast these with the experiences of the recovered cohort

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BMC Psychiatry

RESEARCH

Open Access

## Life experienced as worth living and beyond: a qualitative study of the pathways to recovery and flourishing amongst individuals treated for borderline personality disorder



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Questions?

Thank you

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