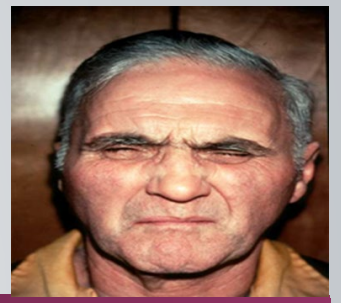
PATIENT EXPERIENCE OF LIVING WITH BENIGN ESSENTIAL BLEPHAROSPASM



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Supported: Moorfields Eye Hospital

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BENIGN ESSENTIAL BLEPHAROSPASM (BEB)

BEB is a rare, progressive chronic neurological disorder characterised by intermittent or sustained muscular contraction of the eyelid and upper face which results in closure of the eyelid/functional blindness, it causes distress and could lead to suicidal thoughts (Berardelli, et al 2021)

COST VS QUALITY CARE

- Globally chronic disorders are a significant challenge
- Health Indicator Report by sex (2019-2020)
- 52.5% GP appointment (GP Survey 2021) 64% Outpatients Kings Fund Report (2012)
- Increase cost to the NHS
- The NHS Long-Term Plan (NHS, 2019)

BACKGROUND/RESEARCH GAP

- Scarcity of BEB literature
- Little known Epidemiological knowledge (prevalence, onset, severity)
- Underdiagnosed condition (poor accuracy, numerous GP consultations)- Wakakura, 2018
- Lack of information/support -Rare Disease UK (RDUK, 2016)
- Policy makers have advocated patient empowerment/patient centred care (DHSC, 2021)

MY ROLE

- Personal observation
- Patient feedback
- Botulinum toxin RCT -safety and effectiveness (Costa et al., 2005)
- BTX offers temporary and varied efficacy (Jinnah et al., 2013).
- No contraindication to a shorter treatment cycle (Jankovic et al., 2011)

RESEARCH STUDY AIM & QUESTIONS

Aim:

Explore the impact of BEB outpatient treatment and care on the lives' of patients

Questions:

How does an acute episode of BEB affect the patient experience?

How does access to outpatient services during an acute episode impact the patient experience?

What needs to change to ensure outpatients services for people with BEB are responsive to expressed needs?

LITERATURE REVIEW

Scoping Search
963 studies following removal of duplicates
131 potential studies

Identified no qualitative research focused on the experience of people with BEB
N=0

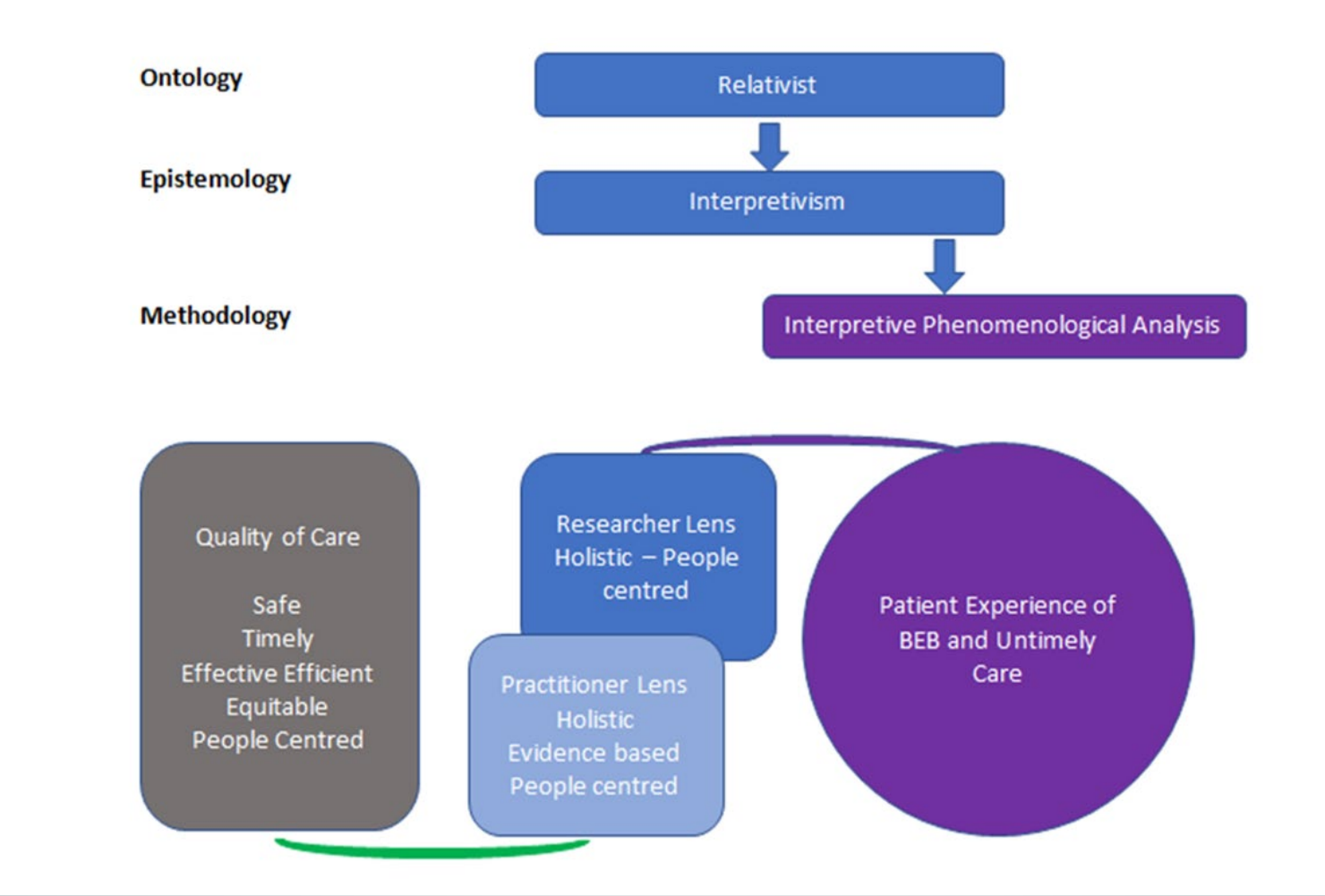
Identified a body of literature focused on measures of Quality of Life
N=56

Narratively reported

Patient narratives
N=25
1 of which was identified in the original search

Meta synthesis

METHODOLOGY



METHODS

Data Collection

- Semi-structured interviews (10)
- Focus group discussion (8 patients + 3 service observers)

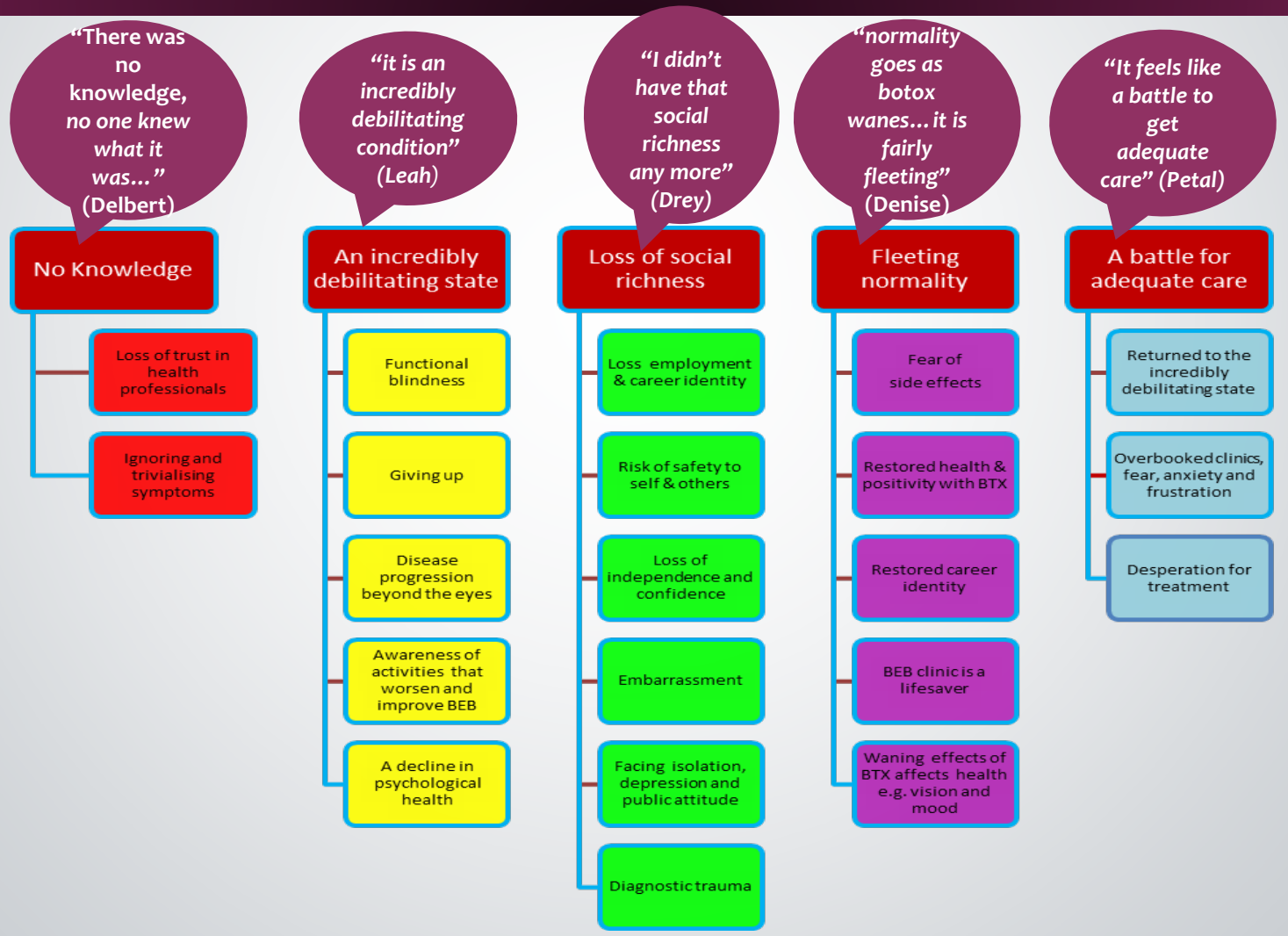
Data Analysis

- IPA - Smith et al. (2009) six step process
- NVivo software

NHS Ethics Service (IRAS)235014
College of Nursing Midwifery and Healthcare at University of West London UWL/REC/CNMH-0032
Moorfields Eye Hospital Research Approval DUNN01

LIVED EXPERIENCE FINDINGS

- 5 Superordinate
- 21 Subordinate



META-SYNTHESIS FINDINGS

- Synthesis 1 (8 Conclusions 2 Categories)
  - Diagnostic knowledge should be improved- prompt referral to reduce negative impact on QOL
- Synthesis 2 (5 Conclusions 1 Category)
  - Improve access to care and treatment ameliorate physical and psychological health symptoms

IMPROVING SERVICE -FOCUS GROUP FINDINGS

- Create a holistic multidisciplinary clinic
- Create a sense of community and continuous learning
- Eliminate demographic disparity
- Provision of more nurse-led clinics
- Being able to communicate with a specialist during acute relapse
- Clerical customer training

DISCUSSION

- **Effective** – Evidence-based healthcare knowledge was lacking in primary care
- **Safe** – poor avoidance of harm to people in primary and secondary care
- **People-centred** – the provision of care did not respond to individual preferences, needs and values.
- **Timely** – waiting times to access care was harmful
- **Equitable** – provision of care varied in quality on account of assertiveness, geographic location, and socio-economic status;
- **Integrated** – a full range of health services was not made available to patient
- **Efficient** – maximizing the benefit of available resources

Practice Impact So Far

Telemedicine Severity BEB Assessment Clinic

Online BEB Focus Group

Introduction of a new nurse-led clinic

New BEB electronic documentation

Optometrist training

National training courses inclusive of satellite nurses

Undertake new junior doctors training

PIFU/Patient Initiated Follow-up

Future

Realisation of timely care

More Nurse-led Clinics within satellite units

Translation of knowledge to primary care

The creation of multidisciplinary clinics

DrDoctor PIFU build sheet – Dystonia 1P and 5A

Service name (for example, Trauma & Orthopaedics PIFU) Patients making requests will see the service name on the Patient Portal.	1. Adnexal Dystonia Clinic- Dyst1P 2. Adnexal Dystonia Clinic –Dyst5A
Is Booking Team already set up on DrDoctor? If not what is the email and phone number of the service, email will be notified when a patients submits a PIFU request	Booking team name: Adnexal Admin Team Booking team phone number: Contact Centre Booking team email address: Moorfields.oncologyandadnexalopteam.nhs.net
Service URL end (Patient facing)	This is the end of the web address Example suggestions : http://my.drdoctor.co.uk/request/moorfields/Dyst1 http://my.drdoctor.co.uk/request/moorfields/Dyst5
Invitation SMS Message Template: From: [[organisation-name]] Dear [[patient-first-name]] [[patient-last-name]], You can make a request for an appointment via [[service-url]]. This service is available to you until [[eligibility-end-date]] Best wishes, [[specialty]] team	From: Moorfields Eye Hospital Dear XXXX, This message is to confirm that following your recent appointment you have been placed on our Patient Initiated Follow-up (PIFU) Pathway. This allows you to contact us our Contact Centre. If indicated, without the need to contact your GP. You can make a request an appointment via http://my.drdoctor.co.uk/request/moorfields/AdnexalLacrimal. The service is available to you until XXXX Best wishes Adnexal Team
Information about your service This section will be shown to patients online on the patient portal. Add some details about your service that your patients may need to know before making a request. E.g make a request if you're experiencing symptoms x,y,z	The Adnexal Dystonia Patient Initiated Follow Up (PIFU) is intended for patients who have increased debilitating spasms and wish timely access to care. Or for patient whose spasm returns later than the standard 3-4 months. Unfortunately you will not be suitable if you had treatment in the last 6-8 weeks. Please provide clear concise information to our Contact Centre to assist them in determining if a PIFU appointment is required.
Thank You Message Template: Thank you, your request has been submitted. We will inform you of the outcome soon.	Thank you, your request has been submitted. We will inform you of the outcome within 72 hours.
Eligibility List	Manual
Service Time Frame and Request frequency **i.e. Length of**	Lifelong Multiple requests

time on the service and multiple requests or on time request	
Patients sent off-boarding message?	From: Moorfields Eye Hospital Dear XXXX, You were previous eligible for an Adnexal Dystonia PIFU appointment during the last 12 months period January 2023 –December 2023. This message confirms you no longer meet the eligibility criteria. Please contact you GP for a new referral and an appointment will then be sent to you by our Contact Centre. Best wishes Adnexal Team
Other information	

CONCLUSION

The lived experience of people with BEB was described as by participants and interpreted by the researcher as a situation where:

- Poor quality of life –social, physical and psychological
- A lack of equitable access to care
- Delays in diagnosis and insufficiency of diagnostic time which made them feel unsafe
- Increased dependency and loss of social identity
- A lack of timeliness and patient-centred care
- Ineffective patient and clinician rapport
- Ineffective co-ordination of care and prolonged suffering

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