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JOURNAL OF THE SOUTHWEST DOCTORAL TRAINING PARTNERSHIP

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THE OPEN REVIEW JOURNAL

JANUARY 2023
EDITION 8

COLLABORATION

THE OPEN REVIEW JOURNAL

JOURNAL OF THE SOUTHWEST DOCTORAL TRAINING PARTNERSHIP

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Editorial

Welcome to the 8th Edition of The Open Review, a journal devoted to supporting academic publication for PhD students across the Universities of Bath, Bristol, Exeter, Plymouth, and the West of England.

I would like to start by extending my heartfelt thanks to our editorial board and contributors. I think all of them will appreciate how their efforts, hard work, and intellect have made TOR's 8th Edition what it is. For this edition's production, the number of submissions has risen exceedingly; and I am only glad that both our members of editorial board and the contributors did much to shorten review times, improve the quality of reviews and also to encourage our authors.

Like its predecessors, the current issue of The Open Review offers its readers a great variety of thought-provoking contributions. The articles in this edition provide an interesting demonstration of the breadth of inclusive research under the theme of *Collaboration*. Research sites are diverse; research questions are both theoretical and practical; a range of quantitative and qualitative research methods are used, including questionnaires, interviews, reflective short essays and a poem dedicated to our theme.

I believe the *Open* in the title stands for something and this edition has achieved decently a far greater reach in hosting quality contributions from diverse formats, perspectives, and contexts. Building on what we understand by the title of our journal, the contents of our issue can testify to the fact that we welcomed submissions from across different disciplines. The 8th edition is not about only drawing on the *collaboration* theme but, also, displays how TOR practices its core values by building collaborative partnerships and ensuring that, behind the scenes, anyone involved performed to their best capabilities in a productive and innovative manner.

It is to be hoped that the communal spirit will continue to build on this momentum in ways that might help to engage specialists and foster inclusivity among early career researchers.

We hope you enjoy this varied selection of articles.

Halime & The Editorial Board

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RESEARCH ARTICLE

How common is fatigue across chronic health conditions in children and young people? A systematic review

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Abstract

Fatigue is a common experience for adults with chronic health conditions. Less is understood about the prevalence of fatigue in the paediatric population. This review aimed to synthesise what is known about the point prevalence of fatigue across chronic health conditions within children and young people. Three databases were searched, from January 2000 to July 2021, to identify studies reporting prevalence rates in chronic health conditions in under 18s. Methodological quality was assessed with a modified version of the Newcastle-Ottawa Scale for Cross-Sectional Studies. Twenty-five studies were included. Variations in the assessment of fatigue, across a range of conditions, and heterogenous reporting of prevalence precluded meaningful meta-analysis and so narrative synthesis was completed. Discrepancies in prevalence reports were noted within and across conditions and between child and parent reports but showed fatigue to be more prevalent in those with chronic health conditions compared to healthy peers. Despite discrepancy in prevalence rates of fatigue, some level of fatigue is present across chronic health conditions and tends to be higher in this population compared to healthy peers. Limitations alongside clinical implications and recommendations for future research are discussed.

Introduction

Fatigue is a subjective experience (Loades & Chalder, 2020), but one that is typically defined as an overwhelming and persistent feeling of tiredness and exhaustion (Dittner et al., 2004), and often associated with a lack of energy which can disrupt daily functioning (de Vries et al., 2010; Ream & Richardson, 1997). Services in the NHS (2022) refer to children and young people as those aged 0 to 18 years and the lifetime prevalence of persistent fatigue within this age group is estimated at 1.29-2.34% (Farmer et al., 2004). In adults, the prevalence of fatigue, which is common and disabling (Small & Lamb, 1999), is higher among those with health conditions (Falk et al., 2007; Goertz et al., 2021). Chronic health conditions refer to illnesses that

are experienced for at least three months, with no cure, and can be lifelong (Law et al., 2019). This includes a broad range of conditions, such as muscular dystrophy, sickle cell disease, and diabetes of which fatigue is reported as a common feature (Ameringer et al., 2014; Bhullar et al., 2018; Segerstedt et al., 2015).

In previous research, fatigue has been described by children and young people with multiple sclerosis (MS) as a heavy 'sandbag'-like feeling, like 'looking through a haze', which impacts physical, mental and emotional wellbeing, with parents understanding the experience as a debilitating and 'uncontrollable tiredness' (Carroll et al., 2016, pp. 940-942). Similar experiences have been reported by adolescents with chronic fatigue syndrome who describe feeling 'drained' and 'worn out' (Parslow et al., 2018, p. 2). These descriptions illustrate the multifaceted nature of fatigue, presenting cognitively and physically (Armbrust et al., 2016), and affecting many areas of life, such as learning, school attendance, and relationships with friends and family (Carroll et al., 2016; Crawley & Sterne, 2009; Garralda & Rangel, 2004; Haig-Ferguson et al., 2009; Winger et al., 2014).

Fatigue may be related to social and environmental triggers (Loades & Chalder, 2020). For those with a chronic health condition, the experience of fatigue may differ from those without a chronic condition due to biological aspects of the condition or treatment (Ameringer et al., 2014). Fatigue experiences in those with chronic health conditions may further differ given the impact on health-related quality of life and adherence to treatment regimens due to difficulties with concentration and memory (Loades & Kagee, 2019). The cognitive behavioural model of fatigue (Surawy et al., 1995) purports that many factors may maintain fatigue, such as cognitive, emotional and behavioural elements, in addition to external reinforcement from others. This model has been supported by further research which shows a relationship between fatigue and a multitude of bio-psycho-social factors, including pain, treatment, low mood, sleep, and performance at school (Armbrust et al., 2016; Carroll et al., 2015; Spathis et al., 2015).

In the paediatric population, previous systematic reviews have considered the prevalence of fatigue within specific health conditions. For example, Armbrust et al., (2016) reported fatigue in 60-76% of children and young people with juvenile idiopathic arthritis. Fatigue was also reported as a concern for children and young people with MS (Carroll et al., 2015), and in children and young people with cancer. However, a lack of relevant studies limited the conclusions that could be drawn on the prevalence and consequences of fatigue for this population (Nowe et al., 2017). Other reviews have explored contributors to fatigue, such as mood, within children and young people with chronic conditions (Carroll et al., 2015; Van de Vijver et al., 2019). One such review (Eddy & Cruz, 2007) found a relationship between fatigue and reduced quality of life in children and young people, aged 8 – 17, with chronic health conditions but noted that the majority of participants fell within the paediatric cancer population. This indicates that less is understood about the prevalence rates of fatigue within other health conditions, and younger children. Further, information from such studies has not yet been synthesised. A recent cross-sectional study of 481 children and young people aged 2 – 18 indicated that fatigue was prevalent across three different chronic conditions which are: cystic fibrosis, cancer, and autoimmune conditions (Nap-Van Der Vlist et al., 2019). That led authors to recommend the need for a systematic assessment of fatigue within this population. Despite these studies, previous research has not synthesised information on point prevalence of fatigue in children and young people with chronic health conditions and doing so would be valuable to inform support offered by clinical teams.

Point prevalence is the proportion of a population currently experiencing a condition, such as fatigue. This provides an estimate on who within a population experiences a condition, at a certain time point, and is often measured with cross-sectional research studies (Migliavaca et al., 2020). Whilst 'prevalence' is closely linked with 'incidence' rates, there is an important distinction to make as reports of incident cases indicate the rate of new cases of a condition within a specific time frame (National Institute of Mental Health, 2017). Reviews of prevalence are key

in managing service provision and policy (Borges Migliavaca et al., 2020).

Despite the frequency with which fatigue is reported as a concern for those with chronic health conditions, and the far reaching consequences of fatigue (Daniel et al., 2013; Loades & Chalder, 2020), it is often overlooked within interventions (Dittner et al., 2004) and under-acknowledged by clinicians (Lou et al., 2010; Sharpe & Wilks, 2002). It is therefore important to systematically understand the prevalence and nature of fatigue to inform services for children and young people which are typically designed for 0–18-year-olds (NHS, 2022). This review therefore aims to synthesise existing knowledge and explore the following research question: What is understood about the point prevalence of fatigue in children and young people, aged 0-18 years, living with chronic health conditions?

Method

The protocol for this review was registered with PROSPERO (CRD42021254251) and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA) guidelines (Page et al., 2021). At the protocol development stage, input from a clinician working within the area of fatigue was sought to maximise the clinical relevance of the review.

Search Strategy

A systematic literature search was conducted using PsycNET, Medline, and Embase databases to identify studies published between January 2000 and July 2021. Search terms were developed in collaboration with a university librarian and based on previous reviews which considered interventions for those with chronic health conditions (Mitchell et al., 2020; Moore et al., 2019; Morey & Loades, 2020) and fatigue (Carroll et al., 2015; Corbett et al., 2019; Spathis et al., 2015). Search terms included both free-text words and Medical Subject Headings (MeSH), with relevant truncations applied to allow variation of search terms. The search strategy focused on four concepts: “child/adolescent/young person”, “chronic health condition”, “fatigue” and “prevalence” and ‘all fields’ were searched in each database. Where possible, database filters were applied to limit searches to studies involving humans, with an age range between 0 – 18 years, and published in English. References of included studies were hand searched to identify further relevant papers that may not have been identified within the database searches.

Eligibility Criteria

Studies were included if a point prevalence of fatigue for children or young people under the age of 18 years was reported, as measured with a validated assessment tool. The age range was chosen following discussion with a clinician working within a paediatric fatigue service and based on the ages of children seen within an NHS paediatric team. When studies included participants over the age of 18 years, we initially planned to contact authors to request data for those only within the 0-18 age bracket. Due to the challenge of obtaining raw data from authors, and following discussion with a clinician, inclusion criteria was adapted to include studies in which participants showed a mean age of 18 years or less.

Criteria for selecting studies included participants with a long term health condition, which persisted for at least three months (Law et al., 2019) and required ongoing management (NHS, 2020). Traumatic brain injury (TBI) conditions were excluded from this study as previous research (Tomar et al., 2018) has indicated an alternative model of fatigue for those with TBI. This alternative model is based on an increased effort required for everyday tasks due to difficulties with cognitive functioning, such as attention and information processing. TBI conditions were also excluded to avoid replication as a recent meta-analysis (Riccardi & Ciccia, 2021) showed fatigue to be a common symptom for children with TBI. Neurodevelopmental conditions were also excluded based on the varying prognoses (Campbell, 2006) which may affect prevalence of

fatigue. In addition, health conditions in which symptoms of fatigue are necessary for diagnosis, such as chronic fatigue syndrome, were excluded. Full eligibility criteria can be found in Table 1.

Table 1

Inclusion and Exclusion Criteria for Papers

Inclusion criteria	Exclusion criteria
Article is available in English	Article not available in English
The paper is peer-reviewed article, reporting on primary data	Paper has a qualitative design only or is not reporting on primary data e.g., systematic review / meta-analysis
Participants are aged 0 – 18 (or sample mean is ≤ 18 years)	Participants are not aged between 0 – 18 years old or the sample mean is 19+
Participants have a chronic health condition, with at least 3 months duration.	Participants do not have a chronic health condition – i.e., a condition that lasts at least 3 months, or traumatic brain injury conditions / chronic fatigue syndrome is reported as the primary diagnosis
Fatigue is a reported outcome, measured using a validated assessment tool	Fatigue is not a primary or secondary outcome and is not measured with a validated tool
Study is quantitative or mixed-methods with a point-prevalence report of fatigue	Point prevalence not measured or reported

Study Selection

Following database searches (29-30th July 2021), Covidence online software was used to remove duplicate papers and screen eligible studies. The records were initially screened based on title and abstract, by two of three independent reviewers, with disagreements resolved through discussion. Inter-rated agreement between the reviewers was ‘fair’ to ‘moderate’ (McHugh, 2012) at 81 – 95% ($\kappa = 0.26$ and $\kappa = 0.52$). For studies that potentially met inclusion criteria, the full text was screened to confirm eligibility by two independent reviewers, with discrepancies discussed and resolved. If full text was not available, authors were contacted to obtain this. Studies were excluded if the papers were unavailable following two attempts to contact authors.

Data Extraction

Data were independently extracted from eligible studies by two reviewers, with use of a data extraction form which was piloted on three studies. Key information for each study, including the design, country, inclusion criteria, age and sex of participants, fatigue measure, and health condition was extracted. Participant sample size and the number of participants who reported fatigue were recorded to calculate prevalence. If data considered relevant to the review were not reported in the full text, study authors were contacted for further information. Studies were again excluded after two attempts at contacting the author.

Quality Assessment

When we preregistered the review protocol (CRD42021254251), we had intended to use the Joanna Briggs Institute (JBI) Prevalence Critical Appraisal Tool (Munn et al., 2015). Subsequently, piloting the tool showed that this was not suitable for all studies. The methodological quality was instead assessed by two independent reviewers using a modified version of the Newcastle-Ottawa Scale (NOS) for Cross-Sectional Studies (Stang, 2010; Zhang et al., 2017).

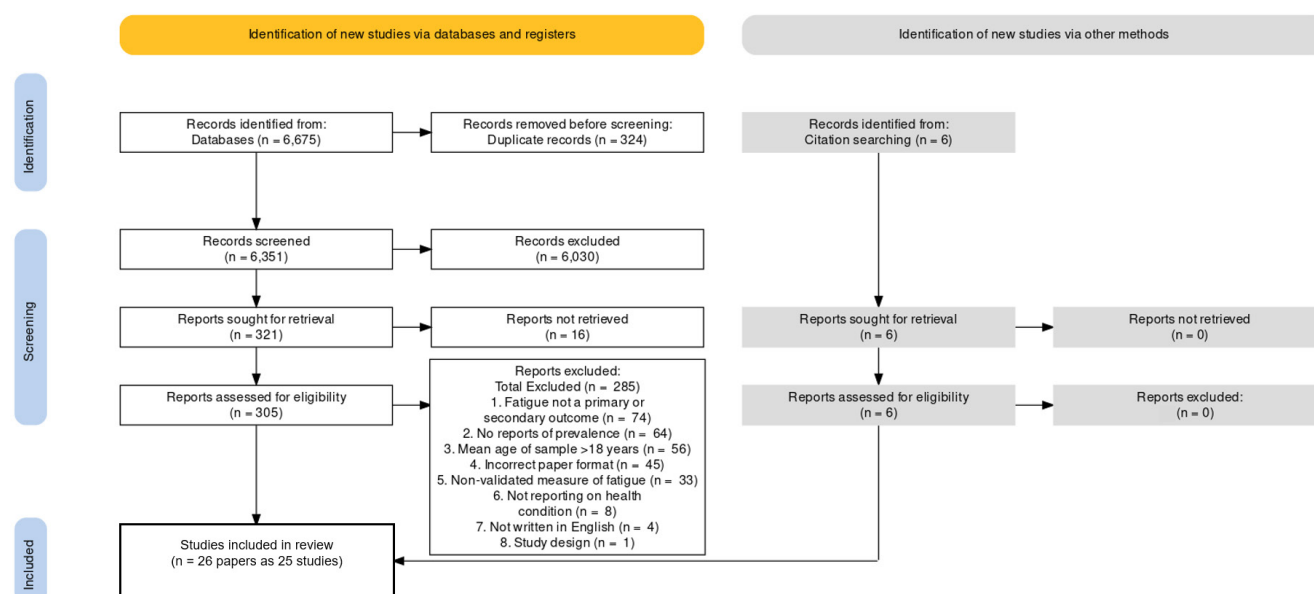
This tool includes six questions focusing on the selection process and representativeness of the sample, along with the quality of outcomes. Studies were assessed as either high quality (>3 points) or low quality (≤3 points). Disagreements were resolved through discussion between the two reviewers.

Data Synthesis

We had intended to conduct a meta-analysis, but this was not possible given the heterogeneity of studies which meant that prevalence statistics could not be reliably pooled together. Instead, a narrative synthesis was used to collate the findings which can offer valuable implications for future research (Arai et al., 2007; Rodgers et al., 2009). The PRISMA reporting guidelines were still followed throughout and the PRISMA flow diagram (Haddaway et al., 2021) (Figure 1) shows details of each stage of the review (Page et al., 2021). The Synthesis Without Meta-Analysis guidelines (Campbell et al., 2020), designed to be used alongside PRISMA standards, were also followed.

Figure 1

PRISMA Flow Diagram, Including Number of Papers Identified, Screened, and Included



Results

Across the three databases, the search strategy identified a total of 6675 articles, from which 324 duplicates were removed. The initial screening stage excluded 6030 papers. The full texts of the remaining 321 articles were reviewed, with 301 papers excluded largely due to not reporting on fatigue prevalence outcomes and the mean age of participants falling above 18 years. Hand searching the reference list of the 20 included papers led to the identification of a further 6 relevant papers, resulting in a total of 26 papers (25 studies) which met the inclusion criteria.

Study Characteristics

The included research studies focused on fatigue in children and young people ($n = 2541$ participants) with a broad range of chronic health conditions, with some papers reporting prevalence data for more than one condition. In total, 12 categories of chronic health condition were reported in the included studies, including cancer (28%), autoimmune conditions (19%) and demyelinating conditions, such as MS (19%). The key characteristics of included studies are summarised in Table 2 below. The sample size within studies ranged from 15 to 481, and age of participants ranged from 2 to 22 years, with a mean age of 12.9 ($SD = 2.9$). Overall, the studies included more participants who identified as female (54%) and were conducted predominantly within the USA (32%) and the Netherlands (24%).

Table 2
Key Characteristics of Each Included Paper

Study (Year) Country	Study Information		Health Condition Information		Age		Gender	
	Design (Setting)	Aim	Sample Size	Chronic health Condition	Medication / Treatment	Mean, SD, Range	F% (n)	M% (n)
Houghton et al. (2008) Canada	Cross sectional (Outpatients)	Assess fitness, fatigue, and quality of life in young people with systemic lupus erythematosus.	15	Systemic lupus erythematosus	100% taking hydroxy-chloroquine; 67% taking prednisone; 67% taking at least 1 noncorticosteroid immunosuppressant	16.5 (1.9) 12.8 – 19.6	80% (12)	20% (3)
MacAllister et al. (2009) United States	Cross sectional (Outpatients)	Assess fatigue and quality of life from child and parental perspective, and explore relationship between fatigue, quality of life and clinical factors in MS	51	Multiple Sclerosis	43% treated with Avonex, Betaseron, Copaxone, or Rebif	14.8 (2.21) 9 - 17	64.7% (33)	35.7% (18)
Ketelslegers et al. (2010) The Netherlands	Cross sectional (Community Clinics)	Determine if children with a demyelinating disease of the central nervous system develop fatigue and investigate relationship with depression and health-related quality of life. Comparison between two chronic conditions and a healthy control group	32	Multiple Sclerosis	9.4% treated with Interferon	15.6 (1.47)	60% (6)	40% (4)
Inocente et al. (2014) France	Cross sectional (Community Clinics)	Explore feelings of depression and correlates in children with narcolepsy	88	Narcolepsy	50% never treated 4.5% stopped treatment 45.5% treated for median of 15 months with one or a combination of modafinil, methylphenidate, mzimindol, venlafaxine, sodium oxybate	12 (NR) 5 – 17.5	50% (44)	50% (44)

Nunes et al. (2017)	Cross sectional (Hospital inpatient)	Investigated factors to explain variance of fatigue symptoms	38	Cancer	Chemotherapy, Surgery, Radiotherapy	12.1 (2.9) 8 – 18	34.2% (13)	65.8% (25)
Donnelly et al. (2018)	Cohort study (Outpatients)	Assess fatigue, pain, psychological symptoms, disease characteristics and health-related quality of life in young people with childhood-onset lupus and identify predictors and risk for reduced health-related quality of life.	50	Childhood-onset lupus	18% at time point 1 prescribed anti-depressant medication	16.2 (2.5) 11 – 20	84% (42)	16% (8)
Fadhilah & Allenidekanya (2019)	Cross sectional (Community)	Explore relationship between fatigue and physical activity in children with leukaemia	45	Acute leukaemia	Most received a chemotherapeutic regimen and were in maintenance phase of chemotherapy	NR (NR) 3 – 16	33.3% (15)	66.7% (30)
Lai et al. (2019)	Cross sectional (Hospital)	Evaluate symptom burden and associated factors in children with brain tumours	199	Brain tumour	86.5% had received radiation, chemotherapy, or surgical treatment within one year of participating in study	14.1 (3.4) 7 – 22	48.4% (96)	51.6% (103)
Petersen et al. (2019)	Cross sectional (Outpatients)	Investigate fatigue and quality of life in recipients of paediatric liver transplant and compare to healthy controls	100	Paediatric liver transplants	NR	12 (4.5) 2.3 – 18.4	47% (47)	53% (53)

Rogers et al. (2019)	Ran- domised con- trolled trial (Hospital inpa- tients)	Primary aim to explore feasibility of a sleep intervention, with secondary aim to investigate relationship between sleep and fatigue	33	Central nervous system cancers	Surgery and 6-weeks of craniospinal radiation	9.5 (3.9) 4 – 19	39.4% (13)	60.6% (20)
United States				Multiple Sclerosis (MS)	NR	15.2 (1.11) 10 – 17	65.4% (17)	34.6% (9)
Florea et al. (2020)	Pro- spective study (Com- munity Clinics)	Explore fatigue, depression symptoms, and quality of life in children with multiple sclerosis and compare with children with acute demyelinating syndromes.	37	Acute Demy- elinating Syn- dromes (ADS)	NR	11.8 (3.11) 10 – 17	54.5% (6)	45.5% (5)
France				Full Sample Group (MS and ADS)	NR		63% (23)	37% (14)
Wrightson et al. (2020)	Cohort study (Popula- tion)	Characterise fatigue in children with perinatal stroke and investigate relationship with motor performance and corticospinal excitability	45	Perinatal stroke	NR	12 (4) 6 – 18	36% (16)	64% (29)
Canada								
Goretti et al. (2012)	Cohort study (Com- munity Clinics)	Assess links between fatigue, depression, and cognitive functioning in a paediatric MS population and compare to healthy control group	57	Multiple Sclerosis	87.7% treated with dis- ease modifying drugs	16.6 (2.5) 11 – 20	54% (31)	46% (26)
Italy								
Jagersma et al. (2013)	Cross sectional (Hospi- tal)	Investigate prevalence of fatigue and assess quality of life in young people with hereditary motor and sensory neuropathy 1A compared to healthy peers and explore effect of fatigue on quality of life	55	Hereditary mo- tor and sensory neuropathy 1A (Charcot-Marie Tooth disease)	NR	15 (2.1) 12 – 18	54.55% (30)	
The Nether- lands								

Orsey et al. (2013)	Prospective study (Hospital)	Investigate relationship between sleep and physical activity in outpatient children with cancer, undergoing treatment	36	Cancer	100% receiving cancer treatment 100% received chemotherapy 30.6% radiation therapy 30.6% steroids	NR (NR) 8 – 18 (10)	27.8% (10)	72.2% (26)
United States								
Maier et al. (2015)	Cross sectional (Children's Services)	Investigate fatigue and correlates in children with physical disabilities	65	Physical disability including cerebral palsy, brain tumour, spina bifida, Charcot-Marie tooth disease, hereditary spastic paraparesis (62% cerebral palsy)	NR	13.2 (2.7) 8 – 17	46% (30)	54% (35)
Australia								
Rodrigues-Nunes et al. (2015)	Descriptive research design with repeated measures (Hospital)	Investigate sleep patterns and fatigue, and factors associated with fatigue	35	Cancer	NR	12.8 (2.7) 8 – 17	51% (18)	49% (17)
United States								
Lai et al. (2016)	Cross sectional (Hospital)	Explore prevalence of carnitine deficiency and its relationship with fatigue in young people with cancer who were on-therapy or off-therapy	150	Cancer or Langerhans cell histiocytosis	Receiving treatment or had completed chemotherapy, radiation therapy, stem cell transplant, or surgery	12.75 (3.2) 8 – 17	40.8% (58)	59.2% (84)
United States								

Nijhof et al. (2016)	Cross sectional (Outpatients)	Investigate prevalence of fatigue and limitations in adolescents with paediatric rheumatic diseases and compare to healthy control group. Assessed effect of pain and disease activity on severity of fatigue	175	Juvenile idiopathic arthritis and other paediatric rheumatic diseases	45% Methotrexate 36% NSAID 48% DMARD 23% biologic agents 12% corticosteroids	14.5 (2.5) 10 – 18	73.7% (129)	26.3% (46)
Coetzee et al. (2018; 2019)	Mixed methods (Community Clinics)	Investigate the predictors and correlates of fatigue within adolescents with HIV	134	Human Immunodeficiency Virus (HIV)	Antiretroviral therapy	14.3 (1.9) 11 – 18	58.2% (78)	41.8% (56)
Nap-van der Vlist et al. (2019)	Cross sectional (Outpatients)	Investigate prevalence and extent of fatigue in children and adolescents with chronic health conditions, and compare with two control groups. Further explored impact of fatigue on health-related quality of life	481	Cystic Fibrosis Autoimmune disease Cancer	NR NR NR	11.3 (5) 11.4 (4.4) 7.7 (5)	51% (57) 65% (179) 46% (43)	49% (54) 35% (98) 54% (50)
Vassallo et al. (2020)	Cross sectional (Outpatients)	Explore prevalence and severity of fatigue in young people with neurofibromatosis type 1 and unaffected siblings	75	Overall Sample Group (all three conditions) Neurofibromatosis type 1	NR NR	10.7 (4.9) 2 – 18	58% (279)	42% (202)
UK								

Zimmerman et al. (2020)	Cross sectional (Outpatients)	Investigate prevalence and severity of symptoms including fatigue, depression, anxiety, and headaches in children with hydrocephalus	40	Hydrocephalus	Surgically treated hydrocephalus, endoscopic third ventriculostomy (ETV), cerebrospinal fluid shunting	13.5 (NR)	50% (20)	50% (20)
United States						7 – 21		
Nap-van der Vlist et al. (2021)	Cross sectional (Outpatients)	Identify biological, psychological, social factors associated with fatigue in children with a chronic disease.	434	Cystic fibrosis Autoimmune disease Post-cancer treatment Full Sample Group (all three conditions)	NR NR NR NR	15.3 (NR)	50.7% (36)	49.3% (35)
The Netherlands						14.4 (NR)	63% (165)	37% (97)
						13.6 (NR)	50.5% (51)	49.5% (50)
						14.5 (NR)	58% (252)	42% (182)
						8 – 18		
Nijhof et al. (2021)	Cross sectional (Outpatients)	Investigate self and parent report of prevalence of fatigue in children and adolescents with primary immunodeficiency and compare findings with healthy peers. Investigate fatigue effect on health-related quality of life and disease-related factors.	79	Primary Immunodeficiency	NR	10.4 (4.4)	40.5% (32)	59.5% (47)
The Netherlands						2 – 18		

Note: SD, Standard Deviation; M, male; F, female; NR, Not Reported; NSAID, Non-Steroidal Anti-Inflammatory Drugs; DMARD, Disease-Modifying Antirheumatic Drugs

Quality Assessment

Thirteen studies were assessed as high quality based on the modified-NOS checklist whilst 12 studies were rated lower quality. The details of this assessment are shown in Table 3 below.

Table 3

Study	Representativeness of the Sample		Sample Size		Ascertainment of the Exposure		Assessment of Outcome (One Point)	Descriptive Statistics Reporting (One Point)	Score	Descriptive
	(One Point)	(One Point)	(One Point)	(One Point)	(One Point)	(One Point)				
Houghton et al. (2008)	0	0	0	0	1	1	1	1	3	Low quality
MacAllister et al. (2009)	0	0	0	0	1	1	1	0	2	Low quality
Ketelslegers et al. (2010)	1	0	0	0	1	1	1	0	3	Low quality
Inocente et al. (2014)	1	0	0	0	1	1	1	0	3	Low quality
Nunes et al. (2017)	0	0	0	0	1	1	1	1	3	Low quality
Donnelly et al. (2018)	0	0	0	0	1	1	1	1	3	Low quality
Fadhilah & Allenidekania (2019)	0	0	0	0	0	0	0	0	0	Low quality
Lai et al. (2019)	1	0	0	0	1	1	1	0	3	Low quality
Petersen et al. (2019)	0	0	0	0	1	1	1	0	2	Low quality
Rogers et al. (2019)	0	0	0	0	1	1	1	0	2	Low quality
Florea et al. (2020)	1	0	0	0	1	1	0	0	2	Low quality
Wrightson et al. (2020)	1	0	0	0	1	1	1	0	3	Low quality
Goretti et al. (2012)	1	0	0	0	1	1	1	1	4	High quality
Jagersma et al. (2013)	1	0	1	1	1	1	1	0	4	High quality
Orsey et al. (2013)	1	0	0	0	1	1	1	1	4	High quality
Maher et al. (2015)	1	0	0	0	1	1	1	1	4	High quality
Rodrigues-Nunes et al. (2015)	1	1	0	0	1	1	1	1	5	High quality
Lai et al. (2016)	1	0	0	0	1	1	1	1	4	High quality
Nijhof et al. (2016)	1	0	0	0	1	1	1	1	4	High quality
Coetzee et al. (2018; 2019)	1	0	0	0	1	1	1	1	4	High quality
Nap-Van Der Vlist et al. (2019)	1	1	1	1	1	1	1	1	6	High quality
Vassallo et al. (2020)	0	0	1	1	1	1	1	1	4	High quality
Zimmerman et al. (2020)	0	1	0	0	1	1	1	1	4	High quality
Nap-Van Der Vlist et al. (2021)	1	0	1	1	1	1	1	1	5	High quality
Nijhof et al. (2021)	0	1	0	0	1	1	1	1	4	High quality

Note. NOS, Newcastle-Ottawa Scale Ratings: High quality 4-6; Low quality 0-3

Results of Quality Assessment Using a Modified-NOS for Cross-Sectional Studies

Measurement of Fatigue

Across the 25 studies, ten measures of fatigue were used with one study (Lai et al., 2016) reporting prevalence based on two different assessment tools. The Paediatric Quality of Life Inventory, which is a Multidimensional Fatigue Scale (PedsQL-MFS) (Varni et al., 2002), was the most commonly used assessment tool and was included in almost half of the studies ($n=12$). All 25 studies asked children or young people themselves to self-rate their levels of fatigue. Additionally, nine studies included a version of parental report; four of which were a parent-proxy rating for children under the age of eight who did not self-report. A further three papers included a parent-child dyad rating in which a caregiver and child both completed a measure of child fatigue. Finally, two recent studies (Petersen et al., 2019; Vassallo et al., 2020) included both proxy and dyad ratings.

Prevalence of Fatigue

Overall, within the included studies ($n=25$), 52 estimates of the prevalence of fatigue were reported with a multitude of heterogeneity based on a diverse combination of groupings of health conditions, age range, severity of fatigue and self or multi-raters. For example, some papers report prevalence based on level of fatigue, with calculations based on participants who meet the threshold for 'severe' fatigue only, whilst other papers report total 'abnormal' fatigue which included those scoring within the mild and moderate ranges on validated assessment tools. Other papers combined multiple health conditions into their grouping of fatigue prevalence whilst some authors calculated the prevalence of fatigue for specific conditions. Additionally, one paper (Rogers et al., 2019) divided prevalence of fatigue into age ranges and reported this separately for child age range (age 4-12 years) and adolescents (age 13-19 years).

Amongst the nine studies that included a form of parental report, further variation was noted. In some of these papers, parental-proxy reports were gathered for children under the age of eight and prevalence scores were reported within the same score as children who were able to complete an assessment of fatigue themselves. Others still created a separate parent-rated grouping for prevalence estimates which included reports from both parent-proxy and parent-dyad measures. This added further complexity and heterogeneity to the data and so prevalence rates cannot be meaningfully pooled into a meta-analysis.

Prevalence estimates based on self-reported levels of fatigue ranged from 5% (Ketelslegers et al., 2010) to 100% (Fadhilah & Allenidekania, 2019) – although both of these studies were rated as low in quality. When taking only high-quality studies into account, self-report prevalence ranged from 14% for total identifiable fatigue (Goretti et al., 2012) to 72% (Lai et al., 2016). As can be seen in Table 4 below, self-ratings of fatigue were notably different to parental reports, with parents in all but one study (Lai et al., 2019) reporting a higher prevalence of fatigue than children and young people reported themselves. Where parent reports were presented separately from self-ratings (6 studies), parental prevalence estimates ranged from 38% (Lai et al., 2019) to 69% (Vassallo et al., 2020) for total identifiable levels of fatigue. In the same studies, prevalence ratings based on self-report from children and young people ranged between 14% (Goretti et al., 2012) and 57% (MacAllister et al., 2009). On average, prevalence based on parental reports was 26% higher than prevalence based on self-reports of fatigue, and the ratings from parents of children with primary immunodeficiency showed the largest discrepancy (43%).

In general, studies that reported higher prevalence were rated as lower in quality; seven studies reported fatigue to be present in over 60% of participants and only one of these studies (Lai et al., 2016) was assessed to be of high quality. The highest prevalence ratings were typically reported in studies with paediatric cancer patients. Of the nine studies within this population, six reported fatigue to be present in over 50% of their sample. Outside of this population, prevalence was reported to be highest and most consistent among those with lupus-conditions.

Two studies (Donnelly et al., 2018; Houghton et al., 2008) explored fatigue in lupus and reported similar prevalence estimates (66 – 67%).

Interestingly, whilst lupus is considered an autoimmune condition, the four other studies which investigated autoimmune disorders within the paediatric community reported much lower prevalence estimates of fatigue. Of the studies that reported separate prevalence ratings for an autoimmune condition, such as HIV and JIA, prevalence estimates ranged from 20 to 25% (Coetzee et al., 2018; Coetzee et al., 2019; Nap-van der Vlist et al., 2021; Nijhof et al., 2016).

Eight of the included studies, six of which were assessed to be high quality, compared fatigue in those with a chronic health condition to either an actively recruited healthy control group ($n=3$) and/or previously published data for healthy controls ($n=6$). Most of these studies ($n=7$) made comparisons based on the level or severity of self-reported fatigue, with five studies demonstrating significantly higher levels of fatigue across chronic health conditions. In addition, some of the studies ($n=3$) drew comparisons based on prevalence of fatigue, with all three studies demonstrating that higher numbers of paediatric patients scored above clinical thresholds for fatigue, compared to healthy peers.

The majority of studies were conducted in the USA ($n=8$) and the Netherlands ($n=6$). Across conditions, studies conducted in the USA reported prevalence ranging from 35 – 71%. In contrast, studies conducted in the Netherlands reported lower prevalence from 16 – 37%.

Factors Associated with Fatigue

The term association refers to a relationship between two variables. The majority of included studies ($n=22$) reported on factors associated with the presence or severity of fatigue and highlighted biopsychosocial components. Seven studies found an association between fatigue and quality of life, with one (Donnelly et al., 2018) longitudinally highlighting that for young people with lupus higher levels of fatigue, alongside depression, predicted poorer quality of life at six month follow up. Overall, symptoms of depression were shown to have a weak to strong relationship with fatigue in five studies, whilst anxiety was explored in only two studies (Coetzee et al., 2018; Zimmerman et al., 2020) and the relationship was non-significant. Difficulties and disturbances with sleep were significantly associated with fatigue in five studies, most commonly showing a weak relationship. Physical functioning was also reported to have a small to moderate relationship with fatigue in four of the studies. Experiences at school, including pressure (one study) and absence (two studies), and social functioning (one study) also showed weak but significant associations with fatigue.

In one study (Rogers et al., 2019), the presence of fatigue was compared across children and adolescents with cancer. This demonstrated a higher prevalence of fatigue in adolescents compared to self-report and parental-proxy report for children under the age of 12. Similarly, Nap-van der Vlist et al., (2021) reported higher levels of fatigue in the older paediatric age group but did not report on how prevalence differed across age ranges. In total, four studies demonstrated weak but significant relationships between fatigue and older age, whilst two studies showed no association in this area (Maher et al., 2015; Wrightson et al., 2020).

Other studies also identified relationships between fatigue and demographics across a range of conditions, including female sex (three studies) and low social economic status (one study). One study with young people with JIA (Nijhof et al., 2016) demonstrated a link between levels of fatigue and pain, however, another five studies, all within the autoimmune population, consistently highlighted no association between fatigue and characteristics of the condition, such as disease activity and treatment.

Table 4
Fatigue Prevalence Across Included Studies

Study (Year)	Chronic health Condition	Measure of Fatigue	Rater	Prevalence of fatigue (numerator/ denominator)	Mean Fatigue Score (SD)	Findings
Houghton et al. (2008)	Systemic lupus erythematosus	Kids Fatigue Severity Scale	Self-report, ages 12-19	66.7% (10/15)	3.8 (1.2)	Fatigue is a major symptom in young people with systemic lupus erythematosus. No significant relationship was found between fatigue and aerobic fitness or quality of life.
MacAllister et al. (2009)	Multiple Sclerosis	PedsQL MFS	Self-report, ages 7-19	Mild 24% (12/49) Severe 32% (16/49) Total 57.1% (28/49)	NR (NR)	Self-report and parent-reports of child fatigue were significantly higher than healthy control samples.
			Parent dyad, ages 7-19	Mild 12% (6/47) Severe 51% (24/47) Total 63.8% (30/47)	NR (NR)	
Ketelslegers et al. (2010)	Multiple Sclerosis Monophasic conditions Full Sample Group (MS and Monophasic conditions)	Checklist Individual Strength	Self-report, ages 11-17	40% (4/10)	NR (NR)	Children with multiple sclerosis were more likely to experience severe fatigue than healthy peers. Fatigue is less likely in children with monophasic inflammatory demyelinating disease. Possible relationship between fatigue and depression and health-related quality of life
				5% (1/22)	NR (NR)	
				16% (5/32)	NR (NR)	
Inocente et al. (2014)	Narcolepsy	Chalder Fatigue Scale	Self-report, ages 5-17	26.7% (23/86)	8 (NR)	A quarter of participants (mostly girls over the age of 10 years) experienced high levels of depression, which were associated with fatigue. Fatigue also correlated with excessive daytime sleepiness, insomnia, and hyperactivity.
Nunes et al. (2017)	Cancer	PedsQL MFS	Self-report, ages 8-18	66.7% (25/38)	63.8 (18.5)	Children and adolescents with cancer had difficulties with three dimensions of fatigue (general, sleep/rest, and cognitive). Significant correlation was found between fatigue and reduced health-related quality of life.
Donnelly et al. (2018)	Childhood-onset lupus	PedsQL MFS	Self-report, ages 11-20	66% (33/50)	58.6 (18.9)	Reduced health-related quality of life at follow up was predicted by higher levels of fatigue and depression symptoms at initial visit.

Fadhilah & Allenidekanya (2019)	Acute lymphocytic leukaemia	Allen's Fatigue in Childhood Cancer Scale	Self-report, ages 3-16	100% (45/45)	Less physically active 10.65 (NR) Physically active 6.27 (NR)	Higher levels of physical activity are associated with lower fatigue in children with leukaemia whilst at home.
Lai et al. (2019)	Brain tumour	PROMIS	Self-report, ages 7-22 Parent dyad, ages 7-22	39% (78/199) 38.3% (76/199)	44.6 (13) NR (NR)	Participants reported less anxiety, depression, and fatigue than the norming sample. Fatigue, anxiety, depression, mobility, peer relationships, and cognition were correlated with symptom distress
Petersen et al. (2019)	Recipients of liver transplant	PedsQL MFS	Self-report, ages 8-18 Parent proxy, ages 2-7 parent dyad, ages 2-18	37% (26/71) 57% (57/100)	74 (15.29) NR (NR)	Children and parents both reported significantly more fatigue than healthy peers. General and cognitive fatigue were significant predictors of health-related quality of life in self report and parent proxy report.
Rogers et al. (2019)	Central nervous system cancers	Fatigue Scale C/A/Parent Fatigue Scale Child / Parent Fatigue Scale Adolescent	Self-report, ages 7-19 Parent proxy, ages 4-6 Self-report, ages 7-12 Parent proxy, ages 4-6 Self-report, ages 13-19	60% (20/33) 53.3% (13/24) 77.8% (7/9)	NR (NR) NR (NR) NR (NR)	Higher levels of fatigue were associated with higher levels of night-time activity and lower percentage of sleep-in adolescents but longer sleep episodes in children - as measured by an actigraph.
Florea et al. (2020)	Multiple Sclerosis Acute Demyelinating Syndromes	Fatigue Severity Scale	Self-report, ages 10-17	43% (10/23) 63% (5/8)	NR (NR) NR (NR)	Fatigue is a key symptom in young people with MS and those with ADS, with children with ADS reporting fatigue more frequently.

Wrightson et al. (2020)	Perinatal stroke	PedsQL-CP	Self-report, ages 8-18	46.6% (21/45)	75 (NR)	Almost half reported experiences of fatigue in the previous month, showing that fatigue is a common experience for children with hemiparesis with perinatal stroke. No relationship found between fatigue and age, type of stroke, or gender.
			Parent proxy, ages 6-8			
Goretti et al. (2012)	Multiple Sclerosis	PedsQL MFS	Self-report, ages 11-20	Mild 9% (5/57) Severe 5% (3/57) Total 14% (8/57)	78.5 (19.8)	A sizeable proportion of children with MS are affected by fatigue and fatigue was significantly associated with higher levels of depressive symptoms. Differences between self- and parent-report fatigue levels is noted.
			Parent dyad, age 11-20	Mild 17.5% (10/57) Severe 21% (12/57) Total 39% (22/57)	74.3 (17.7)	
Jagersma et al. (2013)	Hereditary motor and sensory neuropathy 1A (Charcot-Marie Tooth disease)	Checklist Individual Strength	Self-report, ages 12-18	24% (13/55)	NR (NR)	There is a high prevalence of severe fatigue and reduced quality of life reported in children with hereditary motor and sensory neuropathy 1A, compared with healthy peers.
			Self-report, ages 8-18	58% (21/36)	Child 17 (NR) Adolescent 28 (NR)	
			Self-report, ages 8-18	56% (20/36)	Child 19 (NR) Adolescent 26 (NR)	
Orsey et al. (2013)	Cancer	Fatigue Scale C/A (7 day)	Self-report, ages 8-17	37% (24/65)	65.5 (14.4)	Morning mood negatively correlated with a 7-day rating of fatigue, and sleep quality correlated with both 24 hour and 7-day ratings of fatigue. Whilst fatigue correlates with sleep quality, fatigue on its own was not significantly linked with sleep disturbance.
Maier et al. (2015)	Physical disability including cerebral palsy, brain tumour, spina bifida, Charcot-Marie tooth disease, hereditary spastic paraparesis (62% cerebral palsy)	PedsQL MFS	Self-report, ages 8-17			Fatigue was associated with female gender, low socio-economic status, and being physically inactive. No associations found between fatigue and age, weight, or functional impairment. Those with physical disabilities reported high levels of fatigue compared to other paediatric health populations, with reported fatigue comparable to levels reported in paediatric cancer patients.

Rodrigues-Nunes et al. (2015)	Cancer	PedsQL MFS	Self-report, ages 8-17	54% (19/35)	76.2 (15.4)	Over half of the participants reported difficulties with fatigue at home. Adolescents reported more problems with fatigue than children, and females reported more fatigue than males. Fatigue also varied by cancer diagnosis, with those with sarcoma reporting more fatigue than those with other cancer diagnoses.
Lai et al. (2016)	Cancer or Langerhans cell histiocytosis	pedsFAC-IT-F	Self-report, ages 8-17	56.3% (80/142)	NR (NR)	No significant relationship between fatigue and carnitine levels were found. Those who were currently undergoing treatment reported more severe fatigue than those who had completed cancer treatment.
		PedsQL MFS		71.8% (102/142)	NR (NR)	
Nijhof et al. (2016)	Juvenile idiopathic arthritis and other paediatric rheumatic diseases	Checklist Individual Strength	Self-report, ages 10-18	25.1% (44/175)	28.2 (13.8)	Severe fatigue was associated with increased absence from school and reduced physical functioning. Association found between fatigue and pain, but not with disease activity.
Coetzee et al. (2018; 2019)	HIV	Chalder Fatigue Scale	Self-report, ages 11-18	24.6% (33/134)	14.89 (3.83)	Fatigue was more likely to be reported by older adolescents, those with more difficulties with sleep, and those with higher levels of depression. Depression alone did not account for all fatigue experienced by those with HIV.
Nap-Van Der Vlist et al. (2019)	Cystic Fibrosis Autoimmune disease Cancer Overall Sample Group (all three conditions)	PedsQL MFS	Self-report, ages 8-18 and Parent proxy, ages 2-7	NR (NR/NR)	72 (18.6)	There is a high prevalence of fatigue in children and adolescents with chronic health conditions. Fatigue is likely across disease, age and gender and impacts quality of life.
				NR (NR/NR)	74.5 (18.3)	
				NR (NR/NR)	75.3 (18.6)	
				37% (178/481)	NR (NR)	
Vassallo et al. (2020)	Neurofibromatosis type 1	PedsQL MFS	Self-report, ages 5-18	34% (18/53)	55 (19)	Perceived fatigue affects children with NF1 more than healthy children without NF1.
			Parent proxy, ages 2-4	69% (49/71)	53.5 (20.1)	
Zimmerman et al. (2020)	Hydrocephalus	PROMIS	Parent dyad, ages 5-18	Mild 7.5% (3/40) Moderate 10% (4/40) Severe 15% (6/40) Total 35% (13/40)	45.1 (16.4)	No significant relationship between fatigue, anxiety, depression, or demographics. Mean scores of fatigue, anxiety, and depression were similar to those found in paediatric patients with other chronic health conditions, such as cancer, kidney disease, and asthma.
			Self-report, ages 7-21			

Nap-Van Der Vliet et al. (2021)	Cystic fibrosis	PedsQL MFS	Self-report, ages 8-18	21.1% (15/71) 20.6% (54/262) 26.7% (27/101) 21.8% (95/434)	75 (NR) 75 (NR) 75 (NR) 75 (NR)	Fatigue in children with chronic health conditions is multidimensional and associated with bio-psycho-social factors. Higher levels of fatigue were associated with reduced physical functioning, increased depressive symptoms, more pressure within school, poorer social functioning, and older age.
	Autoimmune disease Post-cancer treatment Full Sample Group (all three conditions)					Fatigue is prevalent in young people with PID. Severe fatigue was linked with increased absence from school and reduced quality of life. It may be beneficial for interventions to focus on fatigue to increase school engagement and quality of life.
Nijhof et al. (2021)	Primary Immunodeficiency	PedsQL MFS	Self-report, ages 8-18	18.9% (10/53)	69.7 (16.9)	Severe fatigue was linked with increased absence from school and reduced quality of life. It may be beneficial for interventions to focus on fatigue to increase school engagement and quality of life.
			Parent proxy, ages 2-7	62.5% (15/24)	61.8 (16.6)	

Note. PedsQL MFS, Paediatric Quality of Life Inventory Multidimensional Fatigue Scale; pedsFACIT-F, Paediatric Functional Assessment of Chronic Illness Therapy-fatigue; PedsQL-CP, Paediatric Quality of Life Inventory Version 3.0 Cerebral Palsy (fatigue subscale); Fatigue Scale C/A, Fatigue Scale Child/Adolescent; PROMIS, Patient Reported Outcome Measurement Information System; NR, not reported; HIV, Human Immunodeficiency Virus; NF1, Neurofibromatosis type 1; MS, Multiple Sclerosis; ADS, Acute Demyelinating Syndrome; PID, Primary Immunodeficiency

Discussion

Our review aimed to explore what is known about the point prevalence of fatigue in children and young people, aged 0 – 18, living with chronic health conditions. A total of 26 papers (25 studies) were captured and findings demonstrated the complexity in understanding the multi-faceted nature of fatigue. In these studies, fatigue was measured with a variety of assessment tools, across a range of conditions, and reported prevalence in heterogenous ways. Overall, 52 rates of prevalence were reported within groups of different health conditions, or reported separately based on specific conditions, severity of fatigue, self-report, and parental reports. The prevalence of fatigue varied widely across studies; including studies assessed as lower quality, prevalence estimates ranged from 5 to 100%, whilst higher quality studies only reported a reduced prevalence range from 14 to 72% based on total identifiable levels of fatigue. Discrepancies were also noted in studies that investigated similar populations, with the prevalence of fatigue in those with MS, for example, ranging from 14 to 57%.

Even within the same study, our understanding of the prevalence of fatigue was mired as vast discrepancies were noted between child reported fatigue and parental reports. The studies showed that parents tended to report a higher prevalence of fatigue than children and young people reported in themselves. Prevalence based on parental report ranged from 38% to almost 70%, whilst the same studies showed that the prevalence of self-reported fatigue ranged from 14 – 57%. These findings are consistent with a previous systematic review (Carroll et al., 2015) which investigated fatigue in children and adolescents with MS and noted similar discrepancies between child and parent reports. Goretti et al., (2012) posit that such discrepancies could be due to under-reporting by children and young people, over-estimating from parents, or a combination of the two. Previous research has demonstrated a relationship between family functioning and fatigue in children with life-threatening health conditions (Huang et al., 2013) which may be reflected in parental responses to fatigue measures. Furthermore, inconsistencies between child and parental reports has been demonstrated in other areas, such as health-related quality of life, with researchers suggesting that wellbeing of parents may impact their report of child symptoms (Eiser & Varni, 2013). It is also possible that child developmental stage affects insight and metacognitive reflective abilities required for self-reporting fatigue, as has been found in health-related quality of life (Conijn et al., 2020), which may further create discrepancies between parent and self-report. This highlights the difficulties in measuring fatigue, both in research and clinically, particularly in young children or those with developmental needs, who may be unable to complete measures themselves. Where possible, it may be beneficial to include multiple perspectives to gather a more thorough sense of how fatigue affects children and young people.

Each of the included studies investigated fatigue in children and young people with different chronic health conditions, at separate stages of condition, and who were accessing different medical regimes. Given that fatigue is a subjective and multi-faceted experience which can be related to biological, psychological, and social factors (Loades & Chalder, 2020; Surawy et al., 1995), as well as treatment regime (Al Maqbali et al., 2021), it is perhaps not unexpected that this review found such a vast range of prevalence reports across studies.

Across the studies, ten measures of fatigue were included, with child and parent versions of the PedsQL-MFS (Varni et al., 2002) used most frequently. This measure was one of only two recommended assessments for children and young people with chronic health conditions in a previous systematic review (Crichton et al., 2015). That review showed the PedsQL-MFS to be a valid measure across conditions and useful for the assessment of younger children, from the age of 2, as well as adolescents up to 18. Of the studies that investigated fatigue in the younger age group, all but one included the PedsQL-MFS. The authors also recommended the Fatigue Scale (Hinds et al., 2010) specifically for a paediatric cancer population. Whilst this assessment was used less often in the included studies, this may be a result of many of the paediatric cancer studies opting to use the PedsQL-MFS as it allows more comparability with other conditions.

Overall, it is promising that over half of the studies incorporated one of the two recommended measures when assessing fatigue.

Despite the discrepancies in measures and prevalence reports, both within and between studies, some commonalities were identified which furthers our understanding of fatigue prevalence in children and young people with chronic health conditions. For example, several studies investigated the presence or severity of fatigue in young people with a chronic health condition and drew comparisons with a sample of healthy peers. In all these studies, a higher prevalence of fatigue was found in those with a chronic health condition, and a further five papers demonstrated an increased severity of fatigue in the chronic health group. This indicates that at least some level of fatigue is common across conditions and affects those with health needs more often than healthy peers. This is consistent with findings from a population-based adult cohort study in which a higher prevalence of participants with one or more chronic conditions reported severe and chronic fatigue compared to those without health conditions (Goërtz et al., 2021).

Studies investigating fatigue in the paediatric cancer population were most common, and in general showed fatigue to be highly prevalent, with six of the nine cancer studies reporting a prevalence of above 50%. Fatigue in young people with cancer fell below this rate when participants had a brain tumour diagnosis and in studies where prevalence was reported in combination with different health conditions. This reported prevalence range in children and young people with cancer appears to be higher than has been found in a recent review by Al Maqbali et al., (2021) that explored prevalence of fatigue in patients with cancer aged 15 and older. Similarly though, the recent review reported significant heterogeneity between studies with variations in prevalence based on treatment and diagnosis.

Many of the studies explored the relationship between fatigue and biological, psychological or social aspects of life, with quality of life, depression, and sleep demonstrated to be most commonly associated with fatigue across conditions. Similar findings have been demonstrated in a recent review which investigated the correlates of fatigue in older adults with chronic health conditions (Torossian & Jacelon, 2021). This could suggest a common underlying pathway of fatigue and associated qualities across health conditions and ages (Hardy & Studenski, 2010). Additionally, these associated factors link to the cognitive behavioural model of fatigue (Surawy et al., 1995) which highlights the role of emotional and behavioural factors in maintaining symptoms of fatigue.

A recent systematic review (Al Maqbali et al., 2021) of those aged 15 and above with cancer showed that fatigue appeared to vary by date, with reported prevalence decreasing by over 20% in recent years. We did not see this pattern in our review. However the prevalence of fatigue did appear to differ between countries, with studies in the US reporting a point prevalence ranging from 35 to 71% whilst prevalence within studies conducted in the Netherlands ranged from 16 to 37%. Whilst this is inconsistent with previous research (De Kleijn et al., 2009) which has shown similar prevalence ratings between adults with sarcoidosis in the US and the Netherlands, it is possible that reports of fatigue may vary across cultures due to assessment of the concept of fatigue or medical regime (Karasz & Mckinley, 2007). It may be helpful for future research to explore this further.

Strengths and Limitations

The exclusion of gray literature and restrictions of language and date, across only three databases, may have excluded some studies relevant to this review. Therefore, we may have missed relevant studies published in other languages, and unpublished studies. It is possible that by restricting our review to published articles, we missed relevant work and we acknowledge that publication bias may have therefore impacted the results, although we deemed this less relevant to our focus on prevalence than it would be in a review focused on statistical significance or effect size as an outcome. Given the heterogeneity within the included studies, it was not

possible to conduct meta-analysis, which further limits the generalisability of the findings. The inclusion, however, of a wide range of chronic health conditions, across different countries, and in populations with a mean age of 18 years or under, strengthens the conclusion that at least some level of fatigue appears to be present across chronic health conditions within children and young people.

Clinical Implications

Whilst previous research suggests that fatigue is often overlooked within healthcare (Ditner et al., 2004), this review indicates that fatigue is common and can be severe in children and young people with chronic health conditions. Therefore, this study recommends that fatigue should be routinely assessed within clinical settings, particularly due to the potential impact on quality of life, mood, and school attendance. Such factors may also be important to consider as part of clinical formulations, based on the cognitive behavioural model of fatigue (Surawy et al., 1995). Discrepancies of symptoms may be common between children and parents, therefore gathering information from multiple sources can inform clinical discussions and allow exploration of family dynamics and impact on family functioning (Vetter et al., 2012). Promising psychological interventions for adolescents with fatigue, including the use of psychoeducation and cognitive behavioural therapy, have been identified in a recent systematic review (Higson-Sweeney et al., 2022) which could be beneficial for children and young people with chronic health conditions. At a service level, the NHS Long Term Plan (NHS, 2019) sets out guidance for joined up care between services. In light of that, this review indicates that collaborative working between health settings and fatigue services may be helpful for children and young people with chronic health conditions.

Future Research

Whilst the majority of studies included an investigation of correlates of fatigue, this was only explored in this review alongside prevalence reports. Based on the findings of this review, it is highly recommended that future research systematically investigates the relationship between fatigue and biological, psychological, and social factors in children and young people with chronic health conditions. Understanding this will allow for potential transdiagnostic interventions within healthcare services. In addition, this review noted discrepancies between child and parental reports of fatigue; further understanding of the variation in symptom reporting may benefit services in gathering information and utilising outcome measures. It is also important to ensure that young people's voices are heard within the evidence-base, therefore qualitative and mixed-method studies will be important to capture the perspectives of children and young people regarding fatigue and its impact on their lives. In future, systematic reviews may look at synthesising mixed-methods or qualitative studies to gain a more thorough understanding of the nature of fatigue within this population.

Conclusion

Understanding the point prevalence of fatigue in children and young people with chronic health conditions is complicated by heterogeneity and discrepancies in estimated prevalence within and between studies. This review, however, shows that some level of fatigue is present across conditions and tends to be higher in those with chronic health conditions compared to healthy peers. A combination of self-report and parental report may be required in services to understand how fatigue affects children and young people and routine screening for fatigue may inform psychological support which could lead to improvements in other areas of life, such as quality of life and mood. Based on the findings and implications of this review, it is recommended that further studies explore the factors associated with fatigue in more detail.

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Biography

Kiesha qualified as a Clinical Psychologist from the University of Bath in September 2022 and now works with children and young people with health conditions. Over the last three years, Kiesha has been conducting a mixed-method study to explore experiences of fatigue for young people with neuromuscular conditions.

Maria is a Reader for the Doctorate in Clinical Psychology programme, University of Bath. Maria qualified as a Clinical Psychologist in 2008 and worked clinically in Child and Adolescent Mental Health (CAMHS), before pursuing teaching and research. Her research focuses on improving access to early help for adolescent depression symptoms.

References

- Al Maqbali, M., Al Sinani, M., Al Naamani, Z., & Al Badi, K. (2021). Prevalence of fatigue in patients with cancer: a systematic review and meta-analysis. *Journal of Pain and Symptom Management*, 61(1), 167-189. e114.
- Ameringer, S., Elswick Jr, R. K., & Smith, W. (2014). Fatigue in adolescents and young adults with sickle cell disease: Biological and behavioral correlates and health-related quality of life. *Journal of Pediatric Oncology Nursing*, 31(1), 6-17. <https://doi.org/10.1177/1043454213514632>
- Arai, L., Britten, N., Popay, J., Roberts, H., Petticrew, M., Rodgers, M., & Sowden, A. (2007). Testing methodological developments in the conduct of narrative synthesis: a demonstration review of research on the implementation of smoke alarm interventions. *Evidence & Policy: A Journal of Research, Debate and Practice*, 3(3), 361-383. <https://doi.org/10.1332/174426407781738029>
- Armbrust, W., Siers, N. E., Lelieveld, O. T. H. M., Mouton, L. J., Tuinstra, J., & Sauer, P. (2016). Fatigue in patients with juvenile idiopathic arthritis: A systematic review of the literature. *Seminars in Arthritis and Rheumatism*, 45(5), 587-595. <https://doi.org/10.1016/j.semarthrit.2015.10.008>
- Bhullar, G., Wei, Y., El-Aloul, B., Speechley, K., Miller, M., & Campbell, C. (2018). Health-related quality of life and fatigue in children with Duchenne muscular dystrophy: A three-year longitudinal study. *Canadian Journal of Neurological Sciences*, 45(s2), S37. <https://doi.org/10.1017/cjn.2018.180>
- Borges Migliavaca, C., Stein, C., Colpani, V., Barker, T. H., Munn, Z., Falavigna, M., & Group, P. E. R. S. R. M. (2020). How are systematic reviews of prevalence conducted? A methodological study. *BMC medical research methodology*, 20(96), 1-9. <https://doi.org/10.1186/s12874-020-00975-3>
- Campbell, B. (2006). *The Patient's Guide to Chronic Fatigue Syndrome & Fibromyalgia*. CSH Press.
- Campbell, M., McKenzie, J. E., Sowden, A., Katikireddi, S. V., Brennan, S. E., Ellis, S., . . . Thomas, J. (2020). Synthesis without meta-analysis (SWiM) in systematic reviews: reporting guideline. *bmj*, 368(16890). <https://doi.org/10.1136/bmj.l6890>
- Carroll, S., Chalder, T., Hemingway, C., Heyman, I., & Moss-Morris, R. (2015). Understanding fatigue in paediatric multiple sclerosis: A systematic review of clinical and psychosocial factors. *Developmental Medicine & Child Neurology*, 58(3), 229-239. <https://doi.org/10.1111/dmnc.12964>
- Carroll, S., Chalder, T., Hemingway, C., Heyman, I., & Moss-Morris, R. (2016). "It feels like wearing a giant sandbag." Adolescent and parent perceptions of fatigue in paediatric multiple sclerosis. *European Journal of Paediatric Neurology*, 20(6), 938-945. <https://doi.org/10.1016/j.ejpn.2016.06.004>

- Coetzee, B., Loades, M. E., Du Toit, S., Read, R., & Kagee, A. (2018). Fatigue among South African adolescents living with HIV: Is the Chalder Fatigue Questionnaire a suitable measure and how common is fatigue? *Vulnerable Children and Youth Studies*, 13(4), 305-316. <https://doi.org/10.1080/17450128.2018.1510147>
- Coetzee, B. J., Loades, M. E., Du Toit, S., & Kagee, A. (2019). Correlates of Fatigue Among South African Adolescents Living with HIV and Receiving Antiretroviral Therapy. *AIDS and behavior*, 23(3), 602-608. <https://doi.org/10.1007/s10461-018-02384-6>
- Corbett, T., Groarke, A., Devane, D., Carr, E., Walsh, J. C., & McGuire, B. E. (2019). The effectiveness of psychological interventions for fatigue in cancer survivors: systematic review of randomised controlled trials. *Systematic reviews*, 8(1), 324. <https://doi.org/10.1186/s13643-019-1230-2>
- Crawley, E., & Sterne, J. A. C. (2009). Association between school absence and physical function in paediatric chronic fatigue syndrome/myalgic encephalopathy. *Archives of Disease in Childhood*, 94(10), 752-756. <https://doi.org/10.1136/adc.2008.143537>
- Crichton, A., Knight, S., Oakley, E., Babl, F. E., & Anderson, V. (2015). Fatigue in Child Chronic Health Conditions: A Systematic Review of Assessment Instruments. *Pediatrics*, 135(4), e1015-e1031. <https://doi.org/10.1542/peds.2014-2440>
- Daniel, L. C., Brumley, L. D., & Schwartz, L. A. (2013). Fatigue in adolescents with cancer compared to healthy adolescents. *Pediatric blood & cancer*, 60(11), 1902-1907. <https://doi.org/10.1002/pbc.24706>
- De Kleijn, W., Elfferich, M., De Vries, J., Jonker, G., Lower, E., Baughman, R., . . . Drent, M. (2009). Fatigue in sarcoidosis: American versus Dutch patients. *Sarcoidosis Vasc Diffuse Lung Dis*, 26(2), 92-97.
- de Vries, J. M., Hagemans, M. L. C., Bussmann, J. B. J., van der Ploeg, A. T., & van Doorn, P. A. (2010). Fatigue in neuromuscular disorders: focus on Guillain–Barre syndrome and Pompe disease. *Cellular and Molecular Life Sciences*, 67(5), 701-713. <https://doi.org/10.1007/s00018-009-0184-2>
- Dittner, A. J., Wessely, S. C., & Brown, R. G. (2004). The Assessment of Fatigue: A practical guide for clinicians and researchers. *Journal of Psychosomatic Research*, 56(2), 157-170. [https://doi.org/10.1016/S0022-3999\(03\)00371-4](https://doi.org/10.1016/S0022-3999(03)00371-4)
- Donnelly, C., Cunningham, N., Jones, J. T., Ji, L., Brunner, H. I., & Kashikar-Zuck, S. (2018). Fatigue and depression predict reduced health-related quality of life in childhood-onset lupus. *Lupus*, 27(1), 124-133. <https://doi.org/10.1177/0961203317716317>
- Eddy, L., & Cruz, M. (2007). The Relationship Between Fatigue and Quality of Life in Children With Chronic Health Problems: A Systematic Review. *Journal for Specialists in Pediatric Nursing*, 12(2), 105-114. <https://doi.org/10.1111/j.1744-6155.2007.00099.x>
- Eiser, C., & Varni, J. W. (2013). Health-related quality of life and symptom reporting: similarities and differences between children and their parents. *European journal of pediatrics*, 172(10), 1299-1304. <https://doi.org/10.1007/s00431-013-2049-9>
- Fadhilah, A., & Allenidekania, A. (2019). The relationship between activity level and fatigue in Indonesian children with acute lymphocytic leukemia in the home setting. *Comprehensive Child and Adolescent Nursing*, 42(Suppl 1), 47-55. <https://doi.org/10.1080/24694193.2019.1577925>
- Falk, K., Swedberg, K., Gaston-Johansson, F., & Ekman, I. (2007). Fatigue is a prevalent and severe symptom associated with uncertainty and sense of coherence in patients with chronic heart failure. *European Journal of Cardiovascular Nursing*, 6(2), 99-104. <https://doi.org/10.1016/j.ejcnurse.2006.05.004>
- Farmer, A., Fowler, T., Scourfield, J., & Thapar, A. (2004). Prevalence of chronic disabling fatigue in children and adolescents [Review]. *British Journal of Psychiatry*, 184(JUNE), 477-481. <https://doi.org/10.1192/bjp.184.6.477>
- Florea, A., Maurey, H., Le Sauter, M., Bellesme, C., Sevin, C., & Deiva, K. (2020). Fatigue, depression, and quality of life in children with multiple sclerosis: a comparative study with other demyelinating diseases. *Developmental medicine and child neurology*, 62(2), 241-244. <https://doi.org/10.1111/dmcn.14242>

- Garraalda, M. E., & Rangel, L. (2004). Impairment and coping in children and adolescents with chronic fatigue syndrome: a comparative study with other paediatric disorders. *Journal of Child Psychology and Psychiatry*, 45(3), 543-552. <https://doi.org/10.1111/j.1469-7610.2004.00244.x>
- Goretti, B., Portaccio, E., Ghezzi, A., Lori, S., Moiola, L., Falautano, M., . . . Pozzilli, C. (2012). Fatigue and its relationships with cognitive functioning and depression in paediatric multiple sclerosis. *Multiple Sclerosis Journal*, 18(3), 329-334. <https://doi.org/10.1177/1352458511420846>
- Goërtz, Y. M., Braamse, A. M., Spruit, M. A., Janssen, D. J., Ebadi, Z., Van Herck, M., . . . Lamers, F. (2021). Fatigue in patients with chronic disease: results from the population-based Lifelines Cohort Study. *Scientific reports*, 11(1), 1-12. <https://doi.org/10.1038/s41598-021-00337-z>
- Haddaway, N. R., McGuinness, L., & Pritchard, C. (2021). PRISMA2020: R package and ShinyApp for producing PRISMA 2020 compliant flow diagrams. <https://doi.org/10.5281/zenodo.4287834>
- Haig-Ferguson, A., Tucker, P., Eaton, N., Hunt, L., & Crawley, E. (2009). Memory and attention problems in children with chronic fatigue syndrome or myalgic encephalopathy. *Archives of Disease in Childhood*, 94(10), 757-762. <https://doi.org/10.1136/adc.2008.143032>
- Hardy, S. E., & Studenski, S. A. (2010). Qualities of fatigue and associated chronic conditions among older adults. *Journal of pain and symptom management*, 39(6), 1033-1042. <https://doi.org/10.1016/j.jpainsymman.2009.09.026>
- Higson-Sweeney, N., Mikkola, A., Smith, L., Shafique, J., Draper, L., Cooper, K., . . . Loades, M. E. (2022). Nonpharmacological interventions for treating fatigue in adolescents: A systematic review and narrative synthesis of randomised controlled trials. *Journal of Psychosomatic Research*, 23(163). <https://doi.org/10.1016/j.jpsychores.2022.111070>
- Hinds, P. S., Yang, J., Gattuso, J. S., Hockenberry, M., Jones, H., Zupanec, S., . . . Srivastava, D. K. (2010). Psychometric and clinical assessment of the 10-item reduced version of the Fatigue Scale-Child instrument [; Research Support, N.I.H., Extramural; Research Support, Non-U.S. Gov't]. *Journal of pain and symptom management*, 39(3), 572-578. <https://doi.org/10.1016/j.jpainsymman.2009.07.015>
- Houghton, K. M., Tucker, L. B., Potts, J. E., & McKenzie, D. C. (2008). Fitness, fatigue, disease activity, and quality of life in pediatric lupus. *Arthritis and rheumatism*, 59(4), 537-545. <https://doi.org/10.1002/art.23534>
- Huang, I. C., Anderson, M., Gandhi, P., Tuli, S., Krull, K., Lai, J. S., . . . Shenkman, E. (2013). The relationships between fatigue, quality of life, and family impact among children with special health care needs. *Journal of Pediatric Psychology*, 38(7), 722-731. <https://doi.org/10.1093/jpepsy/jst016>
- Inocente, C. O., Gustin, M.-P., Lavault, S., Guignard-Perret, A., Raoux, A., Christol, N., . . . Franco, P. (2014). Depressive feelings in children with narcolepsy. *Sleep Medicine*, 15(3), 309-314. <https://doi.org/10.1016/j.sleep.2013.08.798>
- Jagersma, E., Jeukens-Visser, M., Van Paassen, B. W., Meester-Delver, A., & Nollet, F. (2013). Severe fatigue and reduced quality of life in children with hereditary motor and sensory neuropathy 1A. *Journal of Child Neurology*, 28(4), 429-434. <https://doi.org/10.1177/0883073812447681>
- Ketelslegers, I. A., Catsman-Berrevoets, C. E., Boon, M., Eikelenboom, M. J., Stroink, H., Neuteboom, R. F., . . . Hintzen, R. Q. (2010). Fatigue and depression in children with multiple sclerosis and monophasic variants. *European Journal of Paediatric Neurology*, 14(4), 320-325. <https://doi.org/10.1016/j.ejpn.2009.09.004>
- Lai, J. S., Haertling, T., Weinstein, J., Rademaker, A. W., & Goldman, S. (2016). A cross-sectional study of carnitine deficiency and fatigue in pediatric cancer patients [Article]. *Child's Nervous System*, 32(3), 475-483. <https://doi.org/10.1007/s00381-015-2983-0>
- Lai, J. S., Kupst, M. J., Beaumont, J. L., Manley, P. E., Chang, J. H.-C., Hartsell, W. F., . . . Goldman, S. (2019). Using the Patient-Reported Outcomes Measurement Information System (PROMIS) to measure symptom burden reported by patients with brain tumors. *Pediatric blood & cancer*, 66(3), e27526. <https://doi.org/10.1002/pbc.27526>

- Law, E., Fisher, E., Eccleston, C., & Palermo, T. M. (2019). Psychological interventions for parents of children and adolescents with chronic illness. *Cochrane Database of Systematic Reviews*, 18(3), CD009660. <https://doi.org/10.1002/14651858.CD009660.pub4>
- Loades, M. E., & Chalder, T. (2020). Chronic Fatigue in the Context of Pediatric Physical and Mental Illness. In E. Taylor, F. Verhulst, J. Wong, K. Yoshida, & A. Nikapota (Eds.), *Mental Health and Illness of Children and Adolescents. Mental Health and Illness Worldwide*. (pp. 1-8). Springer. https://doi.org/10.1007/978-981-10-0753-8_33-1
- Loades, M. E., & Kagee, A. (2019). Exploring our understanding of fatigue among adolescents living with HIV: highlighting the unknown. *Journal of health psychology*, 24(1), 125-136. <https://doi.org/10.1177/1359105317710320>
- Lou, J. S., Weiss, M. D., & Carter, G. T. (2010). Assessment and management of fatigue in neuromuscular disease. *American Journal of Hospice and Palliative Medicine*, 27(2), 145-157. <https://doi.org/10.1177/1049909109358420>
- MacAllister, W. S., Christodoulou, C., Troxell, R., Milazzo, M., Block, P., Preston, T. E., . . . Krupp, L. B. (2009). Fatigue and quality of life in pediatric multiple sclerosis. *Multiple Sclerosis Journal*, 15(12), 1502-1508. <https://doi.org/10.1177/1352458509345902>
- Maher, C., Crettenden, A., Evans, K., Thiessen, M., Toohey, M., Watson, A., & Dollman, J. (2015). Fatigue is a major issue for children and adolescents with physical disabilities [; Research Support, Non-U.S. Gov't]. *Developmental medicine and child neurology*, 57(8), 742-747. <https://doi.org/10.1111/dmcn.12736>
- McHugh, M. L. (2012). Interrater reliability: the kappa statistic. *Biochemia medica*, 22(3), 276-282.
- Migliavaca, C. B., Stein, C., Colpani, V., Munn, Z., & Falavigna, M. (2020). Quality assessment of prevalence studies: a systematic review. *Journal of Clinical Epidemiology*, 127, 59-68. <https://doi.org/10.1016/j.jclinepi.2020.06.039>
- Mitchell, A. E., Morawska, A., & Mihelic, M. (2020). A systematic review of parenting interventions for child chronic health conditions. *Journal of Child Health Care*, 24(4), 603-628. <https://doi.org/10.1177/1367493519882850>
- Moore, D. A., Nunns, M., Shaw, L., Rogers, M., Walker, E., Ford, T., . . . Shafran, R. (2019). Interventions to improve the mental health of children and young people with long-term physical conditions: linked evidence syntheses. *Health Technology Assessment (Winchester, England)*, 23(22), 1.
- Morey, A., & Loades, M. E. (2020). How has cognitive behaviour therapy been adapted for adolescents with comorbid depression and chronic illness? A scoping review. *Child and adolescent mental health*. <https://doi.org/10.1111/camh.12421>
- Munn, Z., Moola, S., Lisy, K., Riitano, D., & Tufanaru, C. (2015). Methodological guidance for systematic reviews of observational epidemiological studies reporting prevalence and incidence data. *International journal of evidence-based healthcare*, 13(3), 147-153.
- Nap-Van Der Vlist, M. M., Dalmeijer, G. W., Grootenhuis, M. A., Van Der Ent, C. K., Van Den Heuvel-Eibrink, M. M., Wulffraat, N. M., . . . Nijhof, S. L. (2019). Fatigue in childhood chronic disease [Article]. *Archives of Disease in Childhood*, 104(11), 1090-1095. <https://doi.org/10.1136/archdis-child-2019-316782>
- Nap-van der Vlist, M. M., Dalmeijer, G. W., Grootenhuis, M. A., van der Ent, K., van den Heuvel-Eibrink, M. M., Swart, J. F., . . . Nijhof, S. L. (2021). Fatigue among children with a chronic disease: a cross-sectional study. *BMJ paediatrics open*, 5(1). <https://doi.org/10.1136/bmjpo-2020-000958>
- National Institute of Mental Health. (2017). *What is Prevalence?* National Institute of Mental Health,. Retrieved 10 April 2021 from <https://www.nimh.nih.gov/health/statistics/what-is-prevalence.shtml>
- NHS. (2019). *NHS Long Term Plan*. Retrieved 11 November 2022 from <https://www.longtermplan.nhs.uk>
- NHS. (2020). *NHS Business Definitions*. Retrieved 16 August 2020 from https://www.datadictionary.nhs.uk/data_dictionary/nhs_business_definitions//long_term_physical_health_condition_de.asp
- NHS. (2022). *Child or Young Person (Community Services), NHS Data Model and Dictionary*. Retrieved 22 October 2022 from https://www.datadictionary.nhs.uk/nhs_business_definitions/child_or

[young_person_community_services.html](#)

- Nijhof, L. N., van Brussel, M., Pots, E. M., van Litsenburg, R. R. L., van de Putte, E. M., van Montfrans, J. M., & Nijhof, S. L. (2021). Severe Fatigue Is Common Among Pediatric Patients with Primary Immunodeficiency and Is Not Related to Disease Activity [Article in Press]. *Journal of Clinical Immunology*. <https://doi.org/10.1007/s10875-021-01013-7>
- Nijhof, L. N., Van De Putte, E. M., Wulffraat, N. M., & Nijhof, S. L. (2016). Prevalence of Severe Fatigue among Adolescents with Pediatric Rheumatic Diseases [Article]. *Arthritis Care and Research*, 68(1), 108-114. <https://doi.org/10.1002/acr.22710>
- Nowe, E., Stobel-Richter, Y., Sender, A., Leuteritz, K., Friedrich, M., & Geue, K. (2017). Cancer-related fatigue in adolescents and young adults: A systematic review of the literature. *Critical Reviews in Oncology / Hematology*, 118, 63-69. <https://doi.org/http://dx.doi.org/10.1016/j.critrevonc.2017.08.004>
- Nunes, M. D. R., Jacob, E., Bomfim, E. O., Lopes-Junior, L. C., de Lima, R. A. G., Floria-Santos, M., & Nascimento, L. C. (2017). Fatigue and health related quality of life in children and adolescents with cancer. *European journal of oncology nursing : the official journal of European Oncology Nursing Society*, 29, 39-46. <https://doi.org/10.1016/j.ejon.2017.05.001>
- Orsey, A. D., Wakefield, D. B., & Cloutier, M. M. (2013). Physical activity (PA) and sleep among children and adolescents with cancer. *Pediatric blood & cancer*, 60(11), 1908-1913. <https://doi.org/10.1002/pbc.24641>
- Page, M. J., Moher, D., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., . . . Brennan, S. E. (2021). PRISMA 2020 explanation and elaboration: updated guidance and exemplars for reporting systematic reviews. *bmj*, 372(160). <https://doi.org/10.1136/bmj.n160>
- Parslow, R. M., Anderson, N., Byrne, D., Shaw, A., Haywood, K. L., & Crawley, E. (2018). Adolescent's descriptions of fatigue, fluctuation and payback in chronic fatigue syndrome/myalgic encephalopathy (CFS/ME): interviews with adolescents and parents. *BMJ Paediatrics Open*, 2, e000281. <https://doi.org/10.1136/bmjpo-2018-000281>
- Petersen, I., Noelle, J., Buchholz, A., Kroencke, S., Daseking, M., & Grabhorn, E. (2019). Fatigue in pediatric liver transplant recipients and its impact on their quality of life. *Pediatric Transplantation*, 23(1), e13331. <https://doi.org/10.1111/ptr.13331>
- Ream, E., & Richardson, A. (1997). Fatigue in patients with cancer and chronic obstructive airways disease: a phenomenological enquiry. *International Journal of Nursing Studies*, 34(1), 44-53. [https://doi.org/10.1016/S0020-7489\(96\)00032-6](https://doi.org/10.1016/S0020-7489(96)00032-6)
- Rodgers, M., Sowden, A., Petticrew, M., Arai, L., Roberts, H., Britten, N., & Popay, J. (2009). Testing methodological guidance on the conduct of narrative synthesis in systematic reviews: effectiveness of interventions to promote smoke alarm ownership and function. *Evaluation*, 15(1), 49-73. <https://doi.org/10.1177/1356389008097871>
- Rodrigues Nunes, M. D., Jacob, E., Adlard, K., Secola, R., & Nascimento, L. C. (2015). Fatigue and sleep experiences at home in children and adolescents with cancer. *Oncology Nursing Forum*, 42(5), 498-506. <https://doi.org/10.1188/15.ONF.498-506>
- Rogers, V. E., Zhu, S., Ancoli-Israel, S., Liu, L., Mandrell, B. N., & Hinds, P. S. (2019). A pilot randomized controlled trial to improve sleep and fatigue in children with central nervous system tumors hospitalized for high-dose chemotherapy. *Pediatric blood & cancer*, 66(8), e27814. <https://doi.org/10.1002/pbc.27814>
- Segerstedt, J., Lundqvist, R., & Eliasson, M. (2015). Patients with type 1 diabetes in Sweden experience more fatigue than the general population. *Journal of clinical & translational endocrinology*, 2(3), 105-109. <https://doi.org/10.1016/j.jcte.2015.06.001>
- Sharpe, M., & Wilks, D. (2002). ABC of Psychological Medicine: Fatigue. *British Medical Journal*, 325(7362), 480-483. <https://doi.org/10.1136/bmj.325.7362.480>
- Small, S., & Lamb, M. (1999). Fatigue in chronic illness: The experience of individuals with chronic obstructive pulmonary disease and with asthma. *Journal of Advanced Nursing*, 30(2), 469-478. <https://doi.org/10.1046/j.1365-2648.1999.01102.x>
- Spathis, A., Booth, S., Grove, S., Hatcher, H., Kuhn, I., & Barclay, S. (2015). Teenage and Young Adult

- Cancer-Related Fatigue Is Prevalent, Distressing, and Neglected: It Is Time to Intervene. A Systematic Literature Review and Narrative Synthesis [; Review; Systematic Review]. *Journal of adolescent and young adult oncology*, 4(1), 3-17. <https://doi.org/10.1089/jayao.2014.0023>
- Stang, A. (2010). Critical evaluation of the Newcastle-Ottawa scale for the assessment of the quality of nonrandomized studies in meta-analyses. *European journal of epidemiology*, 25(9), 603-605. <https://doi.org/10.1007/s10654-010-9491-z>
- Surawy, C., Hackmann, A., Hawton, K., & Sharpe, M. (1995). Chronic fatigue syndrome: A cognitive approach. *Behaviour Research and Therapy*, 33(5), 534-544. [https://doi.org/10.1016/0005-7967\(94\)00077-W](https://doi.org/10.1016/0005-7967(94)00077-W)
- Torossian, M., & Jacelon, C. S. (2021). Chronic illness and fatigue in older Individuals: A Systematic Review. *Rehabilitation Nursing*, 46(3), 125.
- Van de Vijver, E., Van Gils, A., Beckers, L., Van Driessche, Y., Moes, N. D., & van Rheenen, P. F. (2019). Fatigue in children and adolescents with inflammatory bowel disease. *World journal of gastroenterology*, 25(5), 632. <https://doi.org/10.3748/wjg.v25.i5.632>
- Varni, J. W., Burwinkle, T. M., Katz, E. R., Meeske, K., & Dickinson, P. (2002). The PedsQL™ in pediatric cancer: reliability and validity of the pediatric quality of life inventory™ generic core scales, multi-dimensional fatigue scale, and cancer module. *Cancer*, 94(7), 2090-2106. <https://doi.org/10.1002/cncr.10428>
- Vassallo, G., Mughal, Z., Robinson, L., Weisberg, D., Roberts, S. A., Hupton, E., . . . Stivaros, S. M. (2020). Perceived fatigue in children and young adults with neurofibromatosis type 1. *Journal of Paediatrics and Child Health*, 56(6), 878-883. <https://doi.org/10.1111/jpc.14764>
- Winger, A., Kvarstein, G., Wyller, V. B., Sulheim, D., Fagermoen, E., Sma°stuen, M. C., & Helseth, S. (2014). Pain and pressure pain thresholds in adolescents with chronic fatigue syndrome and healthy controls: A cross-sectional study [Article]. *BMJ Open*, 4(10). <https://doi.org/10.1136/bmjopen-2014-005920>
- Wrightson, J. G., Zewdie, E., Kuo, H.-C., Millet, G. Y., & Kirton, A. (2020). Fatigue in children with perinatal stroke: clinical and neurophysiological associations [; Research Support, Non-U.S. Gov't]. *Developmental medicine and child neurology*, 62(2), 234-240. <https://doi.org/10.1111/dmcn.14273>
- Zhang, L., Fu, T., Yin, R., Zhang, Q., & Shen, B. (2017). Prevalence of depression and anxiety in systemic lupus erythematosus: a systematic review and meta-analysis. *BMC psychiatry*, 17(1), 1-14. <https://doi.org/10.1186/s12888-017-1234-1>
- Zimmerman, K., May, B., Barnes, K., Arynchyna, A., Alford, E. N., Wessinger, C. A., . . . Rocque, B. G. (2020). Anxiety, depression, fatigue, and headache burden in the pediatric hydrocephalus population. *Journal of Neurosurgery: Pediatrics*, 26(5), 483-489. <https://doi.org/10.3171/2020.4>

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SHORT ESSAY

“Drowning in bureaucracy”: The unintended consequences of NHS charging policies for the provision of care to migrant populations

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Over the past decade, the NHS has come under increasing scrutiny, with critics claiming the UK’s healthcare system is “drowning in bureaucracy” due to the introduction of multiple contradictory social policies (Torjesen, 2015, p. 1). This is particularly apparent following the implementation of the 2014 and 2016 Immigration Acts. In an attempt to disincentivise immigration, access to a wealth of social services has been restricted for non-citizens, marking the UK’s shift towards a deliberately hostile environment (Farrington et al., 2016; Kirkup & Winnett, 2012; Weller et al., 2019). More specifically, Theresa May, the then Home Secretary, positioned the rights of migrants as inferior to the rights of others, choosing to limit access to healthcare for those not ‘ordinarily resident’ within the state (Liberty, 2019). Subsequently, these individuals are charged at a rate of 150% for the cost of all non-primary healthcare, and this bill must be paid before they may access NHS support. Although these legal barriers to the accessibility of care pose obvious issues for the wellbeing of migrant populations (Doctors of the World, 2020; Feldman et al., 2019; Russell et al., 2019; Shahvisi, 2019; Walker & Farrington, 2021), further obstacles arise in the inconsistent and often unsuccessful implementation of these policies, exacerbating the impact of hostile environment policies within the migrant population and beyond.

To establish a patient’s charging status, healthcare providers must ask questions regarding the length and nature of their residency. If an individual is found to not be ordinarily resident within the UK, their eligibility for NHS charges will be reported to an Overseas Visitor Manager (OVM), who will pursue them for payment. Despite the attempt to separate the role of caregiver and debt collector, the pursuit of chargeable patients by OVMs is only triggered by the information gathered through the healthcare providers’ initial screening. As such, current policies unintentionally place the onus on NHS staff to carry out bordering practices for which they are neither qualified nor capable of undertaking, leading many to feel as though they have been “turned into border guards” (Goodfellow, 2019, p. 2). This conflict in the responsibilities of NHS clinicians and the impact it has on the wellbeing of migrants and the institution itself lies at the heart of this argument.

Through an appeal to existing literature, this article argues that NHS charging policies are based on an inadequate conceptualisation of migrant health and the practices affecting it. The traditionally positivistic construction of healthcare charging policies has led to various failures within its implementation, which are evidenced by the emergence of ethical and practical layers of bureaucracy within the NHS. More specifically, it is argued that positivism is not *sufficient* for the creation of policy concerning a complex social issue, such as this. With the failures of positivism in mind, it is argued that policymakers must adopt a more collaborative, reflexive, and interdisciplinary approach when creating policies concerning migrant health and care. As such, an appeal to post-normal science is made (Laugharne & Laugharne, 2002). Although this paradigm shift is inherently theoretical, the consequences of it are not. Constructing NHS charging policies from a post-normal scientific perspective would have allowed for the unintended consequences of their implementation to have been foreseen. Accordingly, adjustments could have been made to its original conceptualisation which would have avoided the layers of bureaucracy currently facing NHS staff and patients. Not only would this improve rates of correct exemption identification, enhancing migrant health and wellbeing, but it would also make NHS practices more efficient, benefiting both the institution and its workers.

Background

Positivism: An insufficient paradigm

Historically, knowledge concerning medicine, health, and healthcare has been constructed within a positivist paradigm. Positivism asserts that entities exist independently of being perceived, meaning there is one, tangible and *objective* reality which we can only know through observation. By virtue of its success in the clinical field, positivism has traditionally been viewed as the dominant philosophical paradigm within research (Parke et al., 2020). As such, the majority of knowledge construction concerning *migrant* health has conformed to this positivist paradigm, meaning the nuances and complexities of migration are often overlooked or collapsed *into* the medical aspect of the research (Collins, 2010). This short-sightedness in the construction of migrant health and state policies concerning it constitutes the root cause of the unintended consequences discussed below (Maxwell, 2011). In other words, although traditional science is still *necessary* in the context of policy-making and migrant health more specifically, it is no longer sufficient.

Post-normal science: The solution

Funtowicz (2021) describes post-normal science (PNS) as a decision-making tool, constructed in response to the inadequacies of positivism. The primary function of PNS is to tackle policy issues in which there is a high level of uncertainty and time pressure, yet the stakes are high and have the potential to affect multiple parties (Gallopín et al., 2001, p. 222; Turnpenny et al., 2011, p. 291). This paradigm adopts a broad approach to social problems, also known as *wicked problems*, that are otherwise too complex to be sufficiently distilled via positivism alone (Funtowicz & Ravetz, 2003). Within PNS, all ontologies are viewed as equally valuable, constituting far more knowledge when taken holistically, than when taken individually. This is evident not only through PNS' use of interdisciplinarity, but also its reliance on the collaboration of multiple peer communities. Proponents of this paradigm argue that this holistic process of knowledge construction, alongside the contribution of stakeholders, is essential for policy creation, to generate a response which matches the complexity and diversity of the issue itself (Marshall & Picou, 2008). Importantly, this shift towards PNS is not a rejection of previous research with alternative philosophical perspectives. On the contrary, this paradigm accepts all forms of research and knowledge concerning the issue of healthcare policy, viewing each as contributing something unique and otherwise unattainable (Luks, 1999; van Kerkhoff, 2010). Additionally, PNS does

not claim to *solve* complex social problems, as it acknowledges the fluidity of these issues and rejects the positivist assumption that there is a *right* solution. However, its multifaceted and collaborative approach can push towards a more informed understanding and, therefore, more representative construction of the issue (Petts & Brooks, 2006; Powell, 2020). Specifically, if PNS were employed in the imagining or re-imagining of hostile environment policies, the expertise and experiences of various peer communities would have been drawn on, particularly healthcare providers. This reflexive and inclusive approach would have foreseen (and thus avoided) the unintended consequences of current hostile environment policies (Bochel & Bochel, 2017).

Ethical bureaucracies

In the UK, medical professionals are duty-bound to uphold various ethical standards, as formalised by the *General Medical Council* (2013). These principles are also stated in the *Universal Declaration of Human Rights* (Art. 2) and the UN's *Sustainable Development Goals* (Goal 3.8), highlighting their universally recognised importance to individual and public health outcomes. However, hostile environment policies indirectly force healthcare providers to compromise two defining NHS principles: prioritising the patient and avoiding discrimination. As such, care providers are caught between a professional mandate to protect the wellbeing of the individual and a national policy that requires them to deny access to potentially life-saving support. This is illustrated by Reynolds and Mitchell (2019) in their case study of Albert Thompson, a Windrush migrant who resided in the UK legally for 45 years. In 2017, Albert was diagnosed with prostate cancer and was about to begin radiotherapy, to which he was entitled as a British citizen. However, the Home Office's destruction of the Windrush landing cards led Albert to suddenly be categorised as an *undocumented* migrant. As a result, he was billed £54,000 for his upcoming treatment which he was unable to afford; he was subsequently denied access to this care. Although this example explicitly discusses the impact of charging on migrant communities, it also implicitly comments on barriers to the *provision* of care. Against their moral and professional obligations, healthcare workers were forced to deny treatment, despite knowing this may be fatal for the patient. Synthesising this case study with two professional dilemmas identified by Furman et al. (2007) highlights the ethical layer of bureaucracy resulting from hostile environment policies.

Prioritising patient care

Furman et al. (2007) asked social care students to report how they would hypothetically respond to vulnerable persons who were *morally* entitled to social services, although not legally entitled to them due to strict anti-immigration policies. The central discovery was that even when national policy pushed care workers to value migrant status over health needs, two-thirds of the respondents valued human life over following the law, with one explicitly stating, "because it is lawful does not make it right" (p. 142). Some participants even confessed to adopting illicit strategies such as a "Don't Ask, Don't Tell" method, as they were willing to "risk the fine or jail time" to allow vulnerable persons to access care (p. 143). This is a clear indication of the extent to which healthcare providers will go to fulfil their professional and moral obligations. However, the legal consequences of following these duties do constitute a concern for others, who stated that they would have to obey the national laws, due to fears of losing their jobs (e.g. "I have a family to think about", p. 144) or their organisations being closed down (e.g. "[We could] not help other women and children", p. 142).

Forcing clinicians to uphold immigration restrictions within appointments clearly damages the therapeutic relationship that is essential to the wellbeing of the patient. Moreover, even where migrants are entitled to free healthcare, for example if accessing emergency services, these individuals are deterred from seeking support, due to fears of charging. This is shown to negatively impact the individual, the public, the institution, and even the economy (de Jong et

al., 2017; Jones et al., 2019; Mipatrini et al., 2017). As previously mentioned, stakeholders play an integral part in the construction of knowledge through PNS. With this in mind, had PNS been used to create this hostile environment policy, peer communities would have been consulted throughout the process, meaning the experiences and concerns of healthcare providers would have been considered. As such, this layer of ethical bureaucracy would have been identified and amendments could have been made, benefiting both patients and clinicians.

Avoiding discrimination

There is also a concern among care providers that the denial of healthcare for those not ordinarily resident constitutes discrimination, thus violating the *2010 Equality Act*. Reynolds and Mitchell (2019) discuss this with reference to the concept of justice in their critique of current policies. Justice is necessarily dependent on the frame used to define a population and as outlined by Beauchamp and Childress (1979), healthcare is inherently borderless, treating all individuals as equals. This fundamentally contradicts the sovereign state's view of justice, which presents the frame as only including ordinary residents. The incompatibility at this purely theoretical level is evident. However, it extends beyond this, again affecting the duties of healthcare workers and subsequently undermining the wellbeing of migrant communities. One of Furman et al.'s (2007) respondents writes that their job is not "to identify the legality of people", while another states they would always assume the patient is "a legal citizen and provide all services available" (p. 142). Evidently, healthcare providers fear that such policies may necessitate racial profiling and compromise the health outcomes of minority individuals, in spite of their residency status (Cutler, 2018; Greenfield, 2019; Maternity Action, 2019). These policies are also at risk of alienating the many migrants who are integral to the NHS, by implicitly stating that some individuals are less entitled to support, simply because of their race (Hiam et al., 2018). The array of stakeholders impacted by hostile environment policies, yet not consulted in their inception, exposes the insufficient nature of a purely positivistic approach to policies concerning migrant health. This, again, necessitates the shift towards PNS within the policy-making process. Facilitating collaboration between policymakers and stakeholders would have allowed the impact of charging practices to be considered from all angles, particularly whether these policies were coherent with NHS principles, clinical obligations, and moral duties. Accordingly, these ethical layers of bureaucracy arising from a short-sighted construction of the complex social issue, could and would have been avoided.

Practical bureaucracies

In addition to these ethical layers of bureaucracy, NHS charging policies are complex and convoluted, with official guidance now reaching over 130 pages (Mahase, 2021). As a result, many care providers do not have a sufficient understanding of the conditions for charging, leading to errors in practice and a lack of consistency across NHS Trusts. This constitutes a practical barrier to the provision of care to vulnerable persons. Such bureaucracy may even leave room for prejudicial interpretation, as confusion translates to a lack of regulatory oversight (Westwood et al., 2016). This effectively permits the imposition of one's own political view in the restriction of healthcare. Any policy which is too convoluted to be understood, not supported by sufficient training resources, and necessitates individual interpretation requires restructuring. Again, the impact on migrant communities is obvious, with many scholars reporting the increasing failure to correctly identify charging exemptions among vulnerable persons (Feldman, 2021; Nellums et al., 2018, 2021; Pellegrino et al., 2021; Smith & Levoy, 2016). However, it is apparent that there are further reaching unintended consequences of this hostile environment practice. The complexity of charging policies exposes a knowledge deficit among healthcare providers, thus undermining the integrity and legitimacy of the institution.

Lack of knowledge

The *General Medical Council's* (2013, p. 6) guide to good practice explains that healthcare providers must be “competent in all aspects of [their] work”, which includes “the law, [General Medical Council] guidance, and other regulations relevant to [their] work”. Despite this, the British Medical Association (2019) found that 18% of workers surveyed across the UK were completely unaware that individuals could be charged for NHS care. Even among those who were aware of these practices, there is widespread confusion. Jones et al. (2019) report that 76% of respondents incorrectly categorised “immediately necessary” care as always exempt from charging. Similarly, 40% of participants in Ipsos MORI’s (2017) study believed that *all* care was chargeable for non-exempt persons. There is also uncertainty surrounding *who* may be chargeable, which disproportionately impacts migrant populations. As Jones et al. (2019) highlight, many healthcare providers are unable to differentiate between migrant groups (e.g., refugees, asylum seekers and undocumented migrants), despite these individuals having different care entitlements. This has devastating consequences for those who are not ordinarily resident within the state, as even where they are legally entitled to care due to an exemption, their accessibility can still be curtailed due to the convoluted nature of these policies.

Jones et al. (2019) also report that less than half of all British Medical Association members felt confident in their knowledge of charging practices, with 72% reporting “some” or “significant” training needs in this area. Similarly, Feldman et al. (2019) reported that care providers do not receive explicit training on charging practices, beyond an optional online learning activity. This lack of training not only contributes to the knowledge deficit among care providers, but also enhances the workload of NHS staff who are tasked with deciphering charging exemptions without sufficient resources or knowledge. This has led 35% of NHS care providers to report an increase in workload since the introduction of charging policies, as well as 70% recognising an overall negative effect on the provision of care by the institution (British Medical Association, 2019). Disseminating incorrect and inconsistent information prevents patients from accessing support and undermines the ability to provide care in an effective and timely manner. The use of PNS in the construction of charging policies would have recognised the practical barriers that would arise for healthcare providers through its collaborative approach, therefore, the role of implementing these policies would have been better delegated to others. As such, healthcare workers would not be burdened with either the administrative or moral responsibility of establishing charging status, as these obligations would fall on individuals who have been trained to carry out these practices and face no moral dilemma in implementing them, namely, OVMs.

Conclusion

The concept of “unintended consequences” has been used throughout this analysis to describe the layers of bureaucracy resulting from NHS charging policies, which compromise the ethical, lawful, and effective provision of NHS care. This concept was initially formulated by Merton (1936), who examined *why* policy outcomes differ from those initially predicted, citing a range of factors including a lack of knowledge of contextual causation and placing too much emphasis on short-term consequences. However, the reason most pertinent to this argument for the use of PNS in policymaking processes is that originators of social policy may have been influenced by certain dominant discourses of the time. As a result, the policy reflects *narrow* concerns and constructions of social problems, that necessarily conflict with a *wider* set of societal values and individual experiences. Accordingly, the emergent bureaucratic processes identified throughout this essay are *unintentional*, but not necessarily *unpredictable*.

This essay has discussed the impact of NHS charging policies for the effective, lawful, and ethical provision of care. The development of ethical and practical layers of bureaucracy

within the institution was discussed as an unintended consequence of this policy, arising from the insufficient nature of positivism. Two areas of ethical bureaucracy were identified, predominantly arising from a conflict between professional duties and national policies. It is evident that the obligation to charge certain individuals for healthcare violates the NHS principles of prioritising the patient and avoiding discrimination in the provision of care. This has a detrimental impact on migrants within the UK, who are denied access to necessary support and generally deterred from seeking care, even where they may be entitled to it. Furthermore, where such policies appear to motivate discrimination in the NHS, this alienates not only the migrant workers who are so valued within the institution, but also ethnic minorities within the broader public, who are unfairly profiled or even incorrectly charged, by virtue of their race. Similarly, a practical layer of bureaucracy was identified, with charging policies being too complex to implement, particularly where healthcare workers receive no training on how to enact them. This greatly impacts the migrant population as some individuals are being incorrectly charged for care they may be freely entitled to. However, it also compromises the wellbeing of healthcare staff and the efficiency of NHS processes. Considering these unintended consequences, this essay finds that the use of PNS in the initial formulation of NHS charging policies would have led to the anticipation of the layers of bureaucracy discussed in this essay, through an appeal to holism, interdisciplinarity and collaboration. In light of this, it is argued that PNS should be utilised in the creation of policy concerning migrant health, to avoid the collateral damage that arises from a unidimensional approach, such as positivism.

Biography

Ella is a first-year PhD student (Sociology) at the University of the West of England. This paper was written as part of her MRes in Social Research and is her first academic publication. Ella's doctoral research examines the importance of sexual and reproductive rights for undocumented migrant women and the practical inaccessibility of these rights within the UK's hostile environment. She welcomes any contact about her article, research interests or potential collaborations.

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References

- Beauchamp, T. L., & Childress, J. F. (1979). *Principles of biomedical ethics*. Oxford University Press.
- Bochel, C., & Bochel, H. (2018). *Making and implementing public policy: Key concepts and issues*. Red Globe Press.
- British Medical Association. (2019). *Delayed, deterred, and distressed: The impact of NHS overseas charging regulations on patients and the doctors who care for them*. <https://www.bma.org.uk/media/1834/bma-overseas-charging-paper-2018.pdf>
- Collins, H. (2010). *Creative research: The theory and practice of research for the creative industries*. AVA Publications.
- Cutler, A. (2018, 10 August). The Government is turning NHS staff into border guards, with potentially tragic consequences. *The Bristol Cable*. <https://thebristolcable.org/2018/08/the-government-trying-to-turn-nhs-staff-into-border-guards-hostile-environment-immigration/>
- de Jong, L., Pavlova, M., Winters, M., & Rechel, B. (2017). A systematic literature review on the use and outcomes of maternal and child healthcare services by undocumented migrants in Europe. *The European Journal of Public Health*, 27(6), 990-997. <https://doi.org/10.1093/eurpub/ckx181>

- Doctors of the World. (2020). *Delays & destitution: An audit of Doctors of the World's hospital access project (July 2018-20)*. <https://www.doctorsoftheworld.org.uk/wp-content/uploads/2018/11/Delays-and-destitution-An-audit-of-Doctors-of-the-Worlds-Hospital-Access-Project-July-2018-20.pdf>
- Equality Act 2010, c.15. <https://www.legislation.gov.uk/ukpga/2010/15/contents>
- Farrington, R., Saleh, S., Campbell, S., Jundi, A., & Worthington, E. (2016). Impact of proposal to extend charging for NHS in England. *The Lancet*, (388), 458-459. [https://doi.org/10.1016/S0140-6736\(16\)31150-3](https://doi.org/10.1016/S0140-6736(16)31150-3)
- Feldman, R. (2021). NHS charging for maternity care in England: Its impact on migrant women. *Critical Social Policy*, 41(3), 447-467. <https://doi.org/10.1177/0261018320950168>
- Feldman, R., Hardwick J., & Malzoni, R. C. (2019). *Duty of care? The impact on midwives of NHS charging for maternity care*. Maternity Action. <https://maternityaction.org.uk/wp-content/uploads/DUTY-OF-CARE-with-cover-for-upload.pdf>
- Funtowicz, S. (2021, 19 October). A quick guide to post-normal science. *Integration and Implementation Insights*. <https://i2insights.org/2021/10/19/guide-to-post-normal-science/>
- Funtowicz, S., & Ravetz, J. (2003, 2 February). Post-normal science. *Internet Encyclopaedia of Ecological Economics*. <https://isecoeco.org/pdf/pstnormsc.pdf>
- Furman, R., Langer, C. L., Sanchez, T. W., & Negi, N. J. (2007). A qualitative study of immigration policy and practice dilemmas for social work students. *Journal of Social Work Education*, 43(1), 133-146. <https://doi.org/10.5175/JSWE.2007.200500532>
- Gallopín, G. C., Funtowicz, S., O'Connor, M., & Ravetz, J. (2001). Science for the 21st century: For social contract to the scientific core. *International Journal of Social Science*, (168), 219-229. <https://doi.org/10.1111/1468-2451.00311>
- General Medical Council. (2013). *Good medical practice (Updated 2020)*. https://www.gmc-uk.org/-/media/documents/good-medical-practice---english-20200128_pdf-51527435.pdf
- Greenfield, P. (2019, 9 September). End NHS maternity charges for vulnerable migrants, say midwives. *The Guardian*. <https://www.theguardian.com/society/2019/sep/09/end-nhs-maternity-charges-for-vulnerable-migrants-say-midwives>
- Goodfellow, M. (2019). *Hostile environment: How immigrants became scapegoats* (2nd ed.). Verso.
- Hiam, L., Steele, S., & McKee, M. (2018). Creating a 'hostile environment for migrants': The British government's use of health service data to restrict immigration is a very bad idea. *Health Economics, Policy, and Law*. 13(2), 107-117. <https://doi.org/10.1017/S1744133117000251>
- Immigration Act 2014*, c.22. <https://www.legislation.gov.uk/ukpga/2014/22/contents/enacted>
- Immigration Act 2016*, c.19. <https://www.legislation.gov.uk/ukpga/2016/19/contents>
- Ipsos MORI. (2017). *Overseas Visitor and Migrant NHS Cost Recovery Programme: Formative Evaluation - Final Report*. https://www.ipsos.com/sites/default/files/2017-04/SRI_Health_DH-cost-recovery-programme-evaluation_main-report_060217.pdf
- Jones, B. L., Finnerty, F., & Richardson, D. (2019). Healthcare charging for migrants in the UK: Awareness and experience of clinicians within sexual and reproductive health and HIV. *Journal of Public Health*, 43(2), 355-360. <https://doi.org/10.1093/pubmed/fdz157>
- Kirkup, J., & Winnett, R. (2012, 25 May). Theresa May interview: 'We're going to give illegal migrants a really hostile reception'. *The Telegraph*. <https://www.telegraph.co.uk/news/0/theresa-may-interview-going-give-illegal-migrants-really-hostile/>

- Laugharne, R., & Laugharne, J. (2002). Psychiatry, postmodernism, and post-normal science. *Journal of the Royal Society of Medicine*, (95), 207-210. <https://doi.org/10.1258/jrsm.95.4.207>
- Liberty. (2019). *A guide to the Hostile Environment*. https://www.libertyhumanrights.org.uk/wp-content/uploads/2020/02/Hostile-Environment-Guide—update-May-2019_0.pdf
- Luks, F. (1999). Post-normal science and the rhetoric of inquiry: Deconstructing normal science? *Futures*, (31), 705-719. [https://doi.org/10.1016/S0016-3287\(99\)00028-2](https://doi.org/10.1016/S0016-3287(99)00028-2)
- Mahase, E. (2021). NHS charging system for migrants harmful, unjust, and not cost effective, report finds. *British Medical Journal*, (375). <https://doi.org/10.1136/bmj.n2872>
- Marshall, B. K., & Picou, J. S. (2008). Post-normal science, precautionary principle, and worst cases: The challenge of twenty-first century catastrophes. *Sociological Inquiry*, 78(2), 230-247. <https://doi.org/10.1111/j.1475-682X.2008.00236.x>
- Maternity Action. (2021). *Breach of trust: A review of implementation of the NHS charging programme in maternity services in England*. <https://maternityaction.org.uk/wp-content/uploads/Breach-of-Trust-report-Sept2021.pdf>
- Maxwell, J. A. (2011). *A realist approach for qualitative research*. SAGE Publications.
- Merton, R. K. (1936). The unanticipated consequences of purposive social action. *American Sociological Review*, 1(6), 894-904. <https://doi.org/10.2307/2084615>
- Mipatrini, D., Addario, S. P., Bertollini, R., Palermo, M., Mannocci, A., La Torre, G., Langley, K., Dembech, M., Barragan Montes, S., & Severoni, S. (2017). Access to healthcare for undocumented migrants: Analysis of avoidable hospital admission in Sicily from 2003 to 2013. *European Journal of Public Health*, 27(3), 459-464. <https://doi.org/10.1093/eurpub/ckx039>
- Nellums, L. B., Rustage, K., Hargreaves, S., Friedland, J. S., Miller, A., & Hiam, L. (2018). *Access to healthcare for people seeking and refused asylum in Great Britain*. Equality and Human Rights Commission. <https://www.equalityhumanrights.com/sites/default/files/research-report-121-people-seeking-asylum-access-to-healthcare-evidence-review.pdf>
- Nellums, L. B., Powis, J., Jones, L., Miller, A., Rustage, K., Russell, N., Friesland, J. S., & Hargreaves, S. (2021). "It's life you're playing with": A qualitative study on experiences of NHS maternity services among undocumented migrant women in England. *Social Science & Medicine*, 270(113610). <https://doi.org/10.1016/j.socscimed.2020.113610>
- Park, Y. S., Konge, L., & Antino Jr., A. R. (2020). The positivism paradigm of research. *Academic Medicine*, 95(5), 690-694. <https://doi.org/10.1097/ACM.0000000000003093>
- Pellegrino, C., Benson, C., & Bragg, R. (2021). *Information-sharing between the NHS and the Home Office in England*. Maternity Action. <https://maternityaction.org.uk/advice/information-sharing-between-the-home-office-and-the-nhs/>
- Petts, J., & Brooks, C. (2006). Expert conceptualisations of the role of lay knowledge in environmental decision making: Challenges for deliberative democracy. *Environment and Planning, A38*, 1045-1059. <https://doi.org/10.1068/a37373>
- Powell, T. C. (2020). Can quantitative research solve social problems? Pragmatism and the ethics of social research. *Journal of Business Ethics*, (167), 41-48. <https://doi.org/10.1007/s10551-019-04196-7>
- Reynolds, J. M. K., & Mitchell, C. (2019). 'Inglan is a bitch': Hostile NHS charging regulations contravene the ethical principles of the medical professions. *Journal of Medical Ethics*, (45), 497-503. <https://doi.org/10.1136/medethics-2019-105419>

- Russell, N. J., Murphy, L., Nellums, L., Broad, J., Boutros., Sigona, N., & Devakumar, D. (2019). Charging undocumented migrant children for NHS healthcare: Implications for child health. *British Medical Journal*, 104(8), 722-724. <https://doi.org/10.1136/archdischild-2018-316474>
- Shahvisi, A. (2019). Austerity or xenophobia: The causes and costs of the “hostile environment” in the NHS. *Health Care Analysis*, (27), 202-219. <https://doi.org/10.1007/s10728-019-00374-w>
- Smith, A. C., & Levoy, M. (2016). *The sexual and reproductive health rights of undocumented migrants: Narrowing the gap between their rights and the reality in the EU*. Platform for International Cooperation on Undocumented migrants. http://picum.org/wp-content/uploads/2017/11/Sexual-and-Reproductive-Health-Rights_EN.pdf
- Torjesen, I. (2015). NHS is “drowning in bureaucracy” and lacks good leaders, says scathing report. *British Medical Journal*, 351(h3901). <https://doi.org/10.1136/bmj.h3901>
- Turnpenny, J., Jones, M., & Lorenzoni, I. (2011). Where now for post-normal science?: A critical review of its development, definitions and uses. *Science, Technology, and Human Values*, 36(3), 287-306. <https://doi.org/10.1177/0162243910385789>
- Universal Declaration of Human Rights, 10 December, 1948, <https://www.refworld.org/docid/3ae6b3712c.html>
- Transforming our world: The 2030 Agenda for Sustainable Development, September, 2015, <https://www.refworld.org/docid/57b6e3e44.html>
- van Kerkhoff, L. (2010). Global inequalities in research: A transdisciplinary exploration of causes and consequences. In: V. A. Brown, J. A. Harris, & J. Y. Russels (Eds.), *Tackling wicked problems: Through transdisciplinary research* (pp. 130-138). Routledge.
- Walker, C., & Farrington, R. (2021). Charging for NHS care and its impact on maternal health. *British Journal of General Practice*, 71(705), 155-156. <https://doi.org/10.3399/bjgp21X715337>
- Weller, S. J., Crosby, L. J., Turnbull, E. R., Burns, R., Miller, A., Jones, L., & Aldridge, R. W. (2019). The negative health effects of hostile environment policies on migrants: A cross-sectional service evaluation of humanitarian healthcare provision in the UK. *Wellcome Open Research*, 4(109). <https://doi.org/10.12688/wellcomeopenres.15358.1>
- Westwood, J., Howard, L. M., Stanley, N., Zimmerman, C., Gerada, C., & Oram, S. (2016). Access to, and experiences of, healthcare services by trafficked people: Findings from a mixed-methods study in England. *British Journal of General Practice*, 794-801. <https://doi.org/10.3399/bjgp16X687073>

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SHORT ESSAY

Not All Change is Created Equal – Understanding Organisational Culture and its Effects on Change

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Abstract

An organisation's ability to change is vital to remaining competitive and maintaining agility in rapidly changing climates. There are a plethora of change management methodologies present in the literature that argue for particular courses of action when considering organisational change. However, previous research into organisational culture has identified that there can be cultural differences between organisations of similar size and that these play a significant role in the change management process. This proposes that some attempts to implement change will be more difficult than others and is especially true when considering change management methodologies that place an emphasis on collaboration against those that do not. This short essay discusses the types of organisational cultures that are reported in the literature, so that organisations can be characterised, and makes comparisons to existing change management methodologies so that readers can better evaluate appropriate methods of change in the future.

Introduction

The ability of an organisation to change is critical in developing and improving organisational quality (Smith, 2011), reacting to external factors or expectations (Howells, 2014) and maintaining a competitive advantage within evermore complex markets (Hana, 2013). Change can be initiated from a number of circumstances, such as;

- Grassroots organisational change, where change managers collect actors at lower levels of seniority to collectively create and manage change (Mars, 2009),
- Programmatic change, where change is planned using a known situation and change

activities are manipulated deliberately to achieve the desired result (Wisegarver, 2019).

- Opportunistic change, where individuals or groups take advantage of unplanned events to enact change. (Wisegarver, 2019).

When considering organisational change, the literature has identified that the implementation of solutions may require a degree of cultural change (Ragsdell, 2000) and that it is critical to consider the internal and external environment that is present in an organisation (Bate, 1994). Furthermore, change management literature already identifies that attempts to implement change should consider how change is constructed (Prajogo and McDermott, 2015). However, this is not reflected in change management methodologies which are often presented as solutions to all change situations.

This short essay presents the hypothesis that organisational culture significantly impacts organisational change and thus should be considered when enacting all change activities. In this case, organisational culture is defined as a set of norms, beliefs, principles and ways of behaving that gives an organisation a distinctive character (Brown, 1995). First, I present a background to the concepts of (1) organisational culture, (2) hero culture versus process culture, and (3) unitarist versus pluralist versus radicalist cultures; and include a discussion on each characteristic and its influences on change. Next, theoretical comparisons are made with the core values of collaboratively focussed and non-collaboratively focussed change management methodologies to identify where change management processes may be more or less applicable to different change environments. Finally, the hypothesis presented in this essay, that organisational culture is a critical attribute in successful organisational change, is re-addressed and theoretical conclusions drawn from the comparisons made.

Background

This section will address the background required to answer the hypothesis proposed in this paper; namely that organisational culture has a direct effect on organisational change. This section will introduce organisational culture as a whole, before detailing cultural characteristics of note that are present in the literature. This background is not exhaustive but serves as an example of how culture can be categorised and considered.

Organisational Culture

The literature identified a total of four properties of organisational culture (Bellot, 2011);

1. Organisational culture exists.
2. Organisational culture is ill-defined and includes contradictions, paradoxes, ambiguity and confusion.
3. Organisational culture is socially constructed by groups with shared experiences.

Organisational culture is unique to a given organisation and is malleable.

Organisational culture has been identified to be created from the beliefs and behaviours of early organisational leaders and interpreted by organisational members to create guiding assumptions (Wilcoxson and Millett, 2000). These interpretations are proposed to be considered sub-consciously, are not easy to change or manipulate and take a long period of time to be accepted as valid (Wilcoxson and Millett, 2000). Inciting change that directly or indirectly contradicts these cultural values and beliefs is therefore proposed to be difficult to implement successfully.

Organisational culture has been identified to have a direct impact on an organisation's management style, understanding of strategy, organisational climate, reward system, leadership and fundamental organisational values (Cameron and Quinn, 2011). Although there are a number of established means of measuring organisational culture, this essay aims to consider

culture more generally through the identification of organisational characteristics. These characteristics are proposed to be a dichotomy between hero and process culture, and the concepts of unitarism, pluralism and radicalism, discussed further below.

Hero Culture versus Process Culture

Crosby (1979) proposed that the early emphasis and value that is placed on the development of suitable organisational processes can lead to unplanned cultural effects. In the event that the processes utilised are not suitable within an organisation, defined as 'poor process quality', then an organisation is proposed to be in an uncertainty environment where management have very little knowledge or control over the overall product or service quality. This poor process quality elicits organisational heroes, due to a lack of suitable process or metrics, who are critical to the success of projects within this uncertain environment as they bring their own expertise or skill sets to manage projects. To summarise the uncertainty environment, it is characterised by poor process quality, a lack of metrics and the utilisation of heroes that conduct workloads the way they see it fit to achieve organisational goals (Crosby, 1979). Examples of an uncertainty environment may include organisations with rapidly changing and varied projects or high-innovation start-ups. On the other hand, when considering organisations that have developed processes that are suitable for their activities, defined as strong process quality, there is absolute certainty. In this case, management is knowledgeable and confident that projects have a suitable level of quality as metrics are utilised throughout. There are no heroes within the organisation as individuals can rely on the processes that have been selected with no detrimental side effects (Crosby, 1979). Examples of the certainty environment would include organisations that work in high control environments, such as aerospace or medical.

However, the argument between poor process quality and strong process quality can be explored further when considering this in collaboration with other literature on organisational culture. First, the literature identified a distinct link between the views of senior management within an organisation and an organisation's culture (O'Reilly, 2014). Next, the values that an organisation has within its culture reflect directly on its choice of design process (Cameron and Quinn, 2011). Finally, as mentioned in this section, the acceptance of process quality is directly linked to either a 'hero culture' or 'process culture' (Crosby, 1979).

In conclusion to the review of hero versus process culture, this analysis identifies that there is an inherent link between senior management, organisational culture, process quality and culture at a design level. This will be explored further when considering its implications on change management as this direct link suggests that organisational culture would directly affect organisational change activities.

Unitarist versus Pluralist versus Radical Cultures

The presence of culture within an organisation can also be broadly categorised into unitarist, pluralist and radicalist cultures (Fox, 1996 and Fox, 1974). This section will aim to describe each of these categories of culture so that its effects on organisational change can be identified.

A unitarist organisation has all members of the organisation sharing the same culture, values and beliefs, and working together to achieve the same goals. This type of organisation is associated with harmony, cooperation, effective leadership, high performance and strong team working (Fox, 1974). In contrast, a pluralist organisation has a number of sub-cultures that may operate independently from one another as different working groups, but all making decisions towards a common goal (Fox, 1974). In this instance, individuals within the organisation may have differing values and beliefs to their immediate colleagues, and in some cases aspects of these cultures may be significant and opposed to one another. Finally, a radicalist culture is considered as two directly opposing classes; a high-paid, low workload, managerial role that gives orders and a low-paid, high work, group of 'order-obeyers' (Fox, 1974). In a radicalist culture both classes believe that a gain for one side results in a loss for the other, meaning that their values

and beliefs are fully opposed. This leads to continuous friction, distrust and a poorly performing organisation.

More recently, unitarism, pluralism and radicalism have been considered within the Relational Quality Index (Kaufman et al, 2020). This measure identified a series of variables that were linked to each cultural category. For example, a high RQI score is linked to a unitarist culture, positive management styles and justice in the workplace. Alternatively a low RQI score is linked to a radicalist culture, distrust between more and less senior roles and organisations with a perception of significant organisational disruption. This again evidences the idea that an organisation's culture directly affects organisational activities, and so will directly affect attempts to incite change.

Importantly, Prajogo and McDermott (2005) proposed that change implementations themselves should be considered from a unitarist or pluralist perspective. A unitarist perspective on change would propose that change is a fixed activity that is being applied to one specific culture and the change must be adopted as a whole to be successful. A pluralist perspective on change would propose that there are multidimensional cultures operating within an organisation and that the change managers should be aware of how proposed changes will be viewed by all cultures that will be involved.

Summary of Organisational Culture

The background presented in this paper serves to outline the importance of understanding organisational characteristics when completing change management activities. First, four properties of organisational culture were identified (Bellot, 2011) and a brief summary of how change is formed, accepted (Wilcoxson and Millet, 2000) and affects organisational activities (Cameron and Quinn, 2011) is proposed.

Next, the background highlighted the concepts of hero culture and process culture, and proposed that there was a direct link between senior management, organisational culture, process quality and culture at a design level. This is incredibly important as this link clearly identifies the influence that an established organisational culture has on several significant areas of an organisation.

Following this, the background considered the difference between cultural (Fox, 1974);

- Unitarism (where employees share one culture),
- Pluralism (where a number of sub-cultures are present),
- Radicalism (where a high seniority culture and a low seniority culture work in opposition to each other).

These key cultural characteristics were found to directly influence the operations of an organisation (Kaufman et al, 2020) and were necessary to consider when determining change management strategy (Prajogo and McDermott, 2005). It is important to remember that the concepts of hero culture versus process culture and unitarist versus pluralist versus radicalist are not mutually exclusive; an organisation can have a hero culture and be unitarist, pluralist or radicalist as well.

Implications For Change Management

This section will consider the theoretical organisational culture characteristics defined previously and identify how these characteristics may affect organisational change.

Implications of Hero Culture Versus Process Culture

When attempting to enact change, the identification of an organisation as either a hero

culture or a process culture directly impacts the change management techniques that should be considered and should impact the solutions being proposed. These differences will be outlined and discussed within this section. To reiterate, a hero culture is presented in the literature as being identified symptomatically by poor process quality, very few metrics and an onus on individuals processes and knowledge to complete organisational projects. On the other hand, a process culture is presented as having strong process quality, universally accepted metrics and adherence to documented processes.

First, if an organisation culturally does not place value on process quality as a part of its operations then this would indicate that process is not valued. Therefore, an organisation that is identified as being predominantly hero cultured could find that implementing process-based solutions is more challenging than in a process culture as individuals within the organisation must first be convinced of the benefits of process.

Similarly, if a hero culture considers very few metrics as a part of its operations then this would indicate that the use of metrics or measures to control organisational projects may not be culturally accepted. As such, change that utilises metrics considerably or change that considers only the implementation of new metrics may be notably more challenging than that found in a process culture. However, a localised sub-culture of heroes that have culturally similar values could implement metrics at a local scale.

Finally, due to the onus that is placed on heroes within a hero culture to adopt practices that they believe are worthwhile, heroes within this culture may have more of an onus to accept or reject change management projects. This may lead to the devotion of more time and resources from change management activities which may become significant during the course of change. A process culture would likely not find this same issue.

Implications of Unitarism Versus Pluralism Versus Radicalism

As mentioned in the background to this short essay, research has begun to incorporate the concepts of unitarism, pluralism and radicalism as a part of change management activities. This section will theoretically expand on this understanding through a comparison of each category to applied change.

The literature has identified the concept of defining change activities as either unitarist or pluralist (Prajogo and McDermott, 2005) and these can be directly linked to each cultural category. In the case of a unitarist culture, there is one culture to be considerate of and therefore change management solutions can be unitarist. Similarly, in the case of a pluralist culture there are many cultures to be considerate of and so change should be pluralist to maximise the chance of successful implementation. Finally, as a radicalist culture has two opposing cultures, it may not be possible to utilise the theory of unitarist or pluralist change solutions unless a level of commonality is identified and accepted. In this instance, the proposed change should still attempt to be pluralist as that will allow for greater identification of the scope of this commonality.

When a particular change management approach considers sampling, it would also be important to consider the cultural characteristics of an organisation when delivering change. For example, if an organisation has a unitarist culture, a representative sample size would be much smaller than if an organisation had a pluralist culture as the values and beliefs of individuals in a unitarist culture are the same. The pluralist culture, however, may present differences in viewpoint around a particular subject and so a larger sample must be taken to understand how the values held within an organisation differ between different organisational areas. Finally, in a radicalist culture samples should be selected based off of the type of change and change management methodology that is being considered. For instance, a grassroots change project would need to be considered and structured differently to a management driven change project.

Comparison to Existing Change Management Processes

As mentioned in the background of this short essay, the identification of cultural characteristics should directly impact the change management approach that can be taken. This section will detail two change management approaches and provide an argument as to how organisational culture characteristics may make them more or less applicable to particular situations.

The first change management approach considered was proposed by Lewin (1947) who proposed that openness and accountability are vital to generating support for change. All employees within an organisation are informed about all aspects of change and are enabled to collaborate or challenge particular courses of action. Furthermore, change leaders or groups are held accountable for any changes made to the change plan. This change management approach has been noted as facilitating activities such as co-creation well, as participants are involved in the change management process, but is difficult to sustain in times of high pressure or workload over essential tasks (Carlgren, Elmquist and Rauth, 2016).

The second change management methodology considered in this essay was proposed by Kotter (1996) who suggested that an organisation's employees should be viewed as resisters to change and stressed the importance of management-driven change initiatives. This methodology is most commonly portrayed as Kotter's eight step model (Kotter, 1996) and aims to deliver radical change outcomes. Kotter's change management approach is criticised, however as it proposed that change should be accomplished, and change leaders rewarded, at high cost to the employees that are affected by change and in minimising the role that change leadership must take in the change management process (Hughes, 2015).

To reiterate, this short essay hypothesises that the difference in style and emphasis of change management processes make them more suited to some organisational cultures than others. In particular, it proposes that the more collaborative change management approach of Lewin (1947) and the resistance driven approach of Kotter (1996) could lead to differing results due to culture. A brief summary of the theoretical implications of this are presented in the sections below to understand the importance of organisational culture in change management.

Summary of Cultural Categories Comparisons

Hero Culture – Lewin's (1947) change management process enables heroes to challenge and improve proposed change at the cost of time and resources, which may lead to successful implementation. On the other hand, Kotter (1996) proposes that change is fixed which may prevent some heroes from adopting proposed change and leading to failure.

Process Culture – Lewin's (1947) change management process may be slower to enact change than Kotter's (1996) process in a process culture due to its emphasis on employee involvement.

Summary of Category of Culture Comparisons

Unitarist Culture – Both change processes would be suitable for enabling change in a unitarist culture.

Pluralist Culture – The change management process proposed by Lewin (1947) considers all viewpoints in an organisation and so could lead to more supported change at the cost of time and resources. However, Kotter's (1996) change management process does not consider these views which may lead to faster implementation, or implementation failure depending on other organisational factors.

Radicalist Culture – Lewin's (1947) process could identify commonality between high seniority and low seniority groups and allow for change that is supported by both cultures. On the other hand, Kotter's (1996) process would propose that change should be forced, which may

be successful but will lead to poor employee satisfaction.

Conclusions

To reiterate, this short essay proposed the hypothesis that organisational culture is a critical factor in the implementation of organisational change. Considerations were made in this essay for the overarching cultural attributes of hero culture and process culture, and further for unitarist, pluralist and radicalist cultures. This paper first theoretically identified that the presence of any of these cultural characteristics would affect the change solutions that might be accepted within a given organisation.

Next, a discussion on the application of change management methodologies was constructed that considered Lewin's (1947) and Kotter's (1996) change management approaches against the cultural characteristics identified. It proposed that change management processes could be identified to be more suitably applied in different applications, and therefore that not all change can be considered as equal.

This short essay must conclude that organisational culture would theoretically affect organisational change solutions and activities, based on the organisational culture characteristics of hero versus process culture and unitarist versus pluralist versus radicalist culture. Furthermore, this short essay proposes that there are suitable and unsuitable change management methodologies for particular cultural circumstances. Specifically, where cultural characteristics are identified as hero cultured, pluralist or radicalist, collaborative change methodologies may be more suitable than non-collaborative methodologies.

As change has been identified to be vital in delivering key organisational properties, the conclusions of this essay should be paramount when considering other organisations. This essay has identified that there is a significant gap within the literature in understanding how organisational characteristics impact attempts to enact change. This essay also frames change management as dependent on particular organisational characteristics. Further research should aim to develop an empirical understanding of the significance of each of these cultural characteristics in change management and evaluate whether change management methodologies can be optimally selected for certain organisational cultures. This proposal would allow organisations to identify their own cultural characteristics, and what this means in practice, and enact changes accordingly.

Biography

Brandon Robertson is a final year PhD student and associate lecturer at the University of the West of England, aiming to investigate the implementation of novel design processes within Large Engineering Organisations. His research interests are process implementation, organisational change, fluid dynamics, aero engine design, spaceflight and entrepreneurship and he is happy to be contacted about other research projects.

References

- Bate, P. (1994) *Strategies for cultural change*. First Edition. Boston: Butterworth-Heinemann.
- Bellot, J. (2011) Defining and assessing organizational culture. *Nursing forum*. 46 (1), pp. 29–37. doi:10.1111/J.1744-6198.2010.00207.X.
- Brown, A. (1995) *Organisational Culture* [online]. First Edition. (no place) Pitman. [Accessed 23 May 2021].
- Cameron, K.S. and Quinn, R.E. (2011) *Diagnosing and Changing Organizational Culture : Based on the Competing Values Framework*. New Jersey: Jossey-Bass.
- Carlgren, L., Elmquist, M. and Rauth, I. (2016) The Challenges of Using Design Thinking in Industry – Experiences from Five Large Firms. *Creativity and Innovation Management*. 25 (3), pp. 344–362. doi:10.1111/caim.12176.
- Crosby, P. (1979) *Quality is Free: The Art of Making Quality Certain*. 1st Edition. Ohio: McGraw-Hill.
- Fox, A. (1966) *Industrial sociology and industrial relations: an assessment of the contribution which industrial sociology can make towards understanding and resolving some of the problems now being considered by the Royal Commission*. pp. 34. Available from: https://books.google.com/books/about/Industrial_Sociology_and_Industrial_Rel.html?id=ASYfPwAACAAJ [Accessed 30 May 2021].
- Fox, A. (1976) Beyond Contract: Work, Power and Trust Relations. Alan Fox . *American Journal of Sociology* [online]. 82 (1), pp. 239–242. Available from: <https://www.journals.uchicago.edu/doi/abs/10.1086/226288doi:10.1086/226288> [Accessed 30 May 2021].
- Hana, U. (2013) Competitive Advantage Achievement through Innovation and Knowledge. *Journal of Competitiveness*. 5 (1), pp. 82–96. doi:10.7441/joc.2013.01.06.
- Howells, J.R.L., Karataş-Özkan, M., Yavuz, Ç. and Atiq, M. (2014) University management and organisational change: a dynamic institutional perspective. *Cambridge Journal of Regions, Economy and Society* [online]. 7 (2), pp. 251–270. Available from: <https://academic.oup.com/cjres/article/7/2/251/2864036doi:10.1093/CJRES/RSU005> [Accessed 22 August 2021].
- Hughes, M. (2015) The decline of change management and the rise of change leadership — The University of Brighton. In: *29th Annual British Academy of Management Conference* [online]. 2015 Portsmouth: Portsmouth Business School. pp. 1–18. Available from: <https://research.brighton.ac.uk/en/publications/the-decline-of-change-management-and-the-rise-of-change-leadershi> [Accessed 31 August 2021].
- Kaufman, B.E., Barry, M., Wilkinson, A., Lomas, G. and Gomez, R. (2020) Using unitarist, pluralist, and radical frames to map the cross-section distribution of employment relations across workplaces: A four-country empirical investigation of patterns and determinants: *Journal of Industrial Relations* [online]. 63 (2), pp. 204–234. Available from: <https://journals.sagepub.com/doi/full/10.1177/0022185620977578doi:10.1177/0022185620977578> [Accessed 30 May 2021].
- Kotter, J. (1996) *Leading Change* [online]. Massachusetts: Harvard Business School Press. [Accessed 31 August 2021].
- Lewin, K. (1947) Frontiers in Group Dynamics: Concept, Method and Reality in Social Science; Social Equilibria and Social Change. <https://doi.org/10.1177/001872674700100103> [online]. 1 (1), pp. 5–41. Available from: <https://journals.sagepub.com/doi/abs/10.1177/001872674700100103doi:10.1177/001872674700100103> [Accessed 20 July 2021].
- Mars, M.M. (2009) Student Entrepreneurs as Agents of Organizational Change and Social Transformation: a Grassroots Leadership Perspective. *Journal of Change Management* [online]. 9 (3), pp. 339–357. Available from: https://www.researchgate.net/publication/233313089_Student_Entrepre

neurs_as_Agents_of_Organizational_Change_and_Social_Transformation_a_Grassroots_Leadership_Perspectivedoi:10.1080/14697010903125597 [Accessed 23 August 2021].

O'Reilly, C.A., Caldwell, D.F., Chatman, J.A. and Doerr, B. (2014) The Promise and Problems of Organizational Culture: CEO Personality, Culture, and Firm Performance. *Group and Organization Management*. 39 (6), pp. 595–625.

O'Reilly, C.A., Chatman, J. and Caldwell, D.F. (1991) PEOPLE AND ORGANIZATIONAL CULTURE: A PROFILE COMPARISON APPROACH TO ASSESSING PERSON-ORGANIZATION FIT. *Academy of Management Journal*. 34 (3), pp. 487–516. doi:10.2307/256404.

Prajogo, D.I. and McDermott, C.M. (2005) The relationship between total quality management practices and organizational culture. *International Journal of Operations and Production Management* [online]. 25 (11), pp. 1101–1122. Available from: www.emeraldinsight.com/researchregister doi:10.1108/01443570510626916 [Accessed 30 May 2021].

Ragsdell, G. (2000) Engineering a paradigm shift? An holistic approach to organisational change management. *Journal of Organizational Change Management*. 13 (2), pp. 104–120. doi:10.1108/09534810010321436/FULL/XML.

Smith, I. (2011) Organisational quality and organisational change: Interconnecting paths to effectiveness. *Library Management*. 32 (1), pp. 111–128. doi:10.1108/01435121111102629/FULL/XML.

Willcoxson, L. and Millett, B. (2000) THE MANAGEMENT OF ORGANISATIONAL CULTURE. *Australian Journal of Management & Organisational Behaviour*. 3 (2), pp. 91–99.

Wisegarver, G. (2019) *Opportunistic Change Management Methodology*. Available from: <https://www.forbes.com/sites/forbesfinancecouncil/2019/09/04/opportunistic-change-management-methodology/#56128f3b1b25> [Accessed 9 October 2020].

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RESEARCH ARTICLE

Teachers' Challenges in Times of Protracted Crises in Lebanon

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Abstract

This research study is intended to better understand teachers' perceptions of remote learning during a time of crises in contemporary Lebanon. It does so by examining the perceptions of public and private schoolteachers that are teaching in Lebanon in relation to the educational experiences that are available to them and their students during the severe economic and political crises that started in October 2019 and got intensified by the Covid-19 pandemic and the 2020 Beirut blast. The study seeks to offer a richer picture of the current Lebanese binary educational system and the implications of this binary system on teachers' opportunities, working experiences, and commitment to the profession during difficult times. This is set within the context of a longstanding history of educational marketization in Lebanon principally linked to an extensive network of both religious and secular fee-paying private schools that hire mainly qualified teachers and invest in them professionally to gain popularity in the Lebanese community. The study is critical exploratory, and qualitative in nature. It involves semi-structured interviews with a sample of both public and private schoolteachers teaching at different stages in Lebanon. The data collected through the semi-structured interviews are analysed thematically by using Braun and Clarke's six-phase thematic analysis framework. The findings reveal differences between public and private schoolteachers' capabilities of teaching remotely during the closures resulting from the several crises hitting Lebanon in the last three years. Also, the findings show that the teachers from both public

and moderate fee-paying private schools have been pushed to resort to other sources to enhance their income such as working in several schools or planning to leave the country to work abroad and improve their living.

Introduction

People and their families residing in Lebanon have been suffering lately in the last few years of five crises: the conflicting political situation, the refugee crisis, the Covid-19 pandemic, the explosion of port Beirut, and the unprecedented economic and banking crisis. These unprecedented events in the modern history of Lebanon have affected all the citizens' quality of life and well-being including schoolteachers. Schools in Lebanon are divided into both public and private ones. Public schools are funded by the Lebanese government and are free of charge for all Lebanese (Craddock, 2017). Private schools are mostly funded from the parents' pockets, by paying tuition fees that vary between the different types of private schools (Bahous et al., 2011). However, several studies have shown that the more tuition fees are paid at private schools, the better the quality of teaching and services offered (Bahou, 2017).

Teachers in Lebanon have the option to work at either public or private schools and some teachers are working in both sectors. Studies have shown that Lebanese public schools hire teachers on two bases: contract or permanent basis (Mattar, 2012). Public school permanent teachers are ideally hired based on two factors. Firstly, their success in the civil service exam that is conducted every several years (around five years) and then according to the religious distributions which are followed in all the governmental positions in Lebanon (Najjar, 2009). Public school permanent teachers are paid in Lebanese Pounds (LBP), known as Lira, and their salaries were considered good before the Lebanese economic and banking crisis. Their monthly salary includes housing and transport. Also, permanent teachers benefit from the National Social Security Fund (NSSF), end-of-service benefits, and educational allowance for their children and they get a guaranteed job for life (Najjar, 2009). Teachers applying for a fixed term or permanent basis are assigned according to the government's regulations. Successful candidates should pass the civil service exam that is conducted once every four or five years to be recruited permanently and they are distributed among schools according to perceived needs. However, Najjar (2009) pointed out that if a public school principal is on good terms with the general directors of education at the Ministry of Education and Higher Education (MEHE), then they can get qualified teachers, and this, in turn, can increase the gap between the public schools themselves and can increasingly affect the more socioeconomically disadvantaged students in remote areas (Akkary & Greenfield, 1998). Also, Abdul-Hamid and Yassine (2020) illustrated that the political leaders in Lebanon "use the education sector to provide services to their constituents, for example, through the recruitment and deployment of teachers" (p. 16). Thus, clout and clientelism play a significant role in the recruitment process in the education sector. On the other hand, contract-based appointment was introduced to the public education sector during the Lebanese civil war because of the barriers set up between the different Lebanese regions (Mattar, 2012). Abdul-Hamid and Yassine (2020) state that:

sectarian and political considerations, as opposed to competence, were credited for the recruitment of many contractual teachers. As a result, these teachers had not received sufficient preparation in the teaching profession and also have fewer incentives and opportunities for professional development. (p. 36)

Contract-based teachers are paid according to the number of hours they teach per week, and they are not paid for official holidays or events when schools are closed. Also, they are not allowed to register with the NSSF, and they do not receive travelling grants or end-of-service indemnity (Atchan, 2022). Their hourly wage rate is fixed and does not take into consideration seniority or credentials, and they are paid in LBP which has lost an estimated 90% of its value in 2021 making the contracted teachers' salary worth between \$1 or \$2 an hour (Atchan, 2022). This hourly wage got doubled at the beginning of the academic year 2021-2022 in response to several protests to become \$5 per hour in addition to \$90 per month given as a social grant offered by the world bank, particularly for contracted teachers of an amount of \$37,000,000 for the academic year 2021-2022 only (World Bank, 2021). This amount was granted to the MEHE and approved by the civil service board to calm the contracted teachers' continuous strikes and stop the demands for better wages, transportation allowances, and other incentives that can help the contracted teachers survive all the recent changes happening in the country. Mattar (2012) explained that contracted public schoolteachers do not feel secure, and that they are always on strike demanding higher salaries and better working conditions. They get paid once or twice per year and they have no rights as she illustrates. By the beginning of the academic year 2021-2022, the contracted teachers were still struggling and refusing to start teaching at public schools because the minister of education failed in fulfilling the promises as all the decisions require a decree approved by the cabinet which was not meeting at the time of conducting the study for political reasons.

As for teaching in the private education sector several research studies show that there are discrepancies between private and public schools in terms of the quality of teachers hired (Bahous & Nabhani, 2008; Ghamrawi, 2010; Shuayb, 2016). Bahous and Nabhani (2008) state that:

In Lebanon, the Ministry of Education recruits public schoolteachers from the graduates of the national Lebanese University whereas private schools recruit graduates of private universities where the standards of teacher preparation programs are more rigorous than in the Lebanese University in course content, foreign language proficiency, and internship experiences. Moreover, private schools pay higher salaries, attract better-qualified teachers, and have the freedom to terminate the contracts of mediocre staff. (p. 129)

Additionally, most prestigious, and expensive private schools encourage their teachers to continue higher education and they provide the teachers with in-service training based on needs assessment regularly (Baroudi, 2019). This makes the equality of teaching and learning at private schools in general more structured and serious.

In the academic year 2020-2021, there were 92,908 teachers working in Lebanon distributed among the four types of schools (CERD, 2021). 39,519 teachers were working at public schools, 6,456 teachers were working at semi-free private schools, 45,310 teachers were working at fee-paying private schools, and 1,626 teachers were working at the United Nations Relief and Works Agency (UNRWA) for Palestinian refugees' private schools. A study conducted recently revealed that the income of most of the teachers in Lebanon was negatively affected during the pandemic and the subsequent crises (Moghli & Shuayb, 2020). Additionally, a report published by Hammoud et al. (2021) entitled "The Challenges and Prospects of Returning to School" showed that the teachers' socioeconomic status got deteriorated during the pandemic due to salary cuts and this deterioration has affected badly the quality of education at schools. Also, Atchan (2022) illustrates that the current problems in Lebanon are having a detrimental impact on teachers' motivation in the classroom, as well as their connections with their students, students' families, and school administration. Therefore, it is obvious that the last three years (2019 till 2022) were full of challenges and difficulties in Lebanon, and this study attempts to uncover teachers' perceptions during these unprecedented times and to what extent the quality of life that the teachers are having and the challenges they are facing during these extraordinary times are affecting their dedication to work. It also intends to fill in the gaps of current knowledge

in this field and adds up to the growing body of literature written about teachers' perceptions during times of protracted crises.

Research Questions

This study aims to answer the following research questions:

1. How do different teachers, working at either public or private schools, describe the impact of the current crises hitting Lebanon on the education sector?
2. What challenges are faced by both public and private schoolteachers?
3. To what extent are the schoolteachers in Lebanon managing during these extremely difficult times?

Literature Review

Job Satisfaction

Faragher et al. (2013) described job satisfaction at work as the optimistic emotional reactions and positive feelings that people have toward their jobs. Job satisfaction is considered an especially critical issue within all companies and institutions including the education sector and it is widely known that when a worker's needs and demands are met, the level of production increases (Najjar, 2009; Atchan, 2022). In the field of education, job satisfaction is a major aspect that many schools' principals and managements give big attention, to both improve the quality of teaching and the school's efficiency (Akiri, 2014; Amoli & Youran, 2014; Chamundeswari, 2013). Several empirical studies were conducted in this field, and they all showed the importance of creating a motivating work environment and positive school climate that is capable of meeting the teacher's intrinsic and extrinsic needs which are deemed essential for teaching and success (Pearson & Moomaw, 2005; Skaalvik & Skaalvik, 2010). The most common intrinsic factors that influence job satisfaction include but are not limited to self-efficacy, self-growth, self-actualization, and autonomy (Avanzi et al., 2013; Bogler & Nir, 2012). As for the most common extrinsic factors that are stated in the literature range from working conditions, job security, and job salary, to the availability of resources and teaching equipment (Chaudry et al., 2011; Ingersoll, 2001). Therefore, both teachers' intrinsic and extrinsic motivations are essential for enhancing students' learning and success in academia.

Well-being of Teachers

Milkowski (2019) argued that elevated levels of stress are connected with occupations requiring high levels of social communication. On this count, the teaching field encompasses grand stressors compared to other human services jobs. Friedman (2000) argued that the teaching profession is labelled as one of the most demanding and hectic jobs; however, the causes of teachers' stress and frustration differ greatly from one country to another. Therefore, a teacher's well-being is influenced by cultural and social contexts (Roffey, 2012). Similarly, Pepe et al. (2018) illustrated that there is a clear relationship between the teachers' subjective well-being and the places they reside in because economic, social, and religious factors can impact their well-being widely. Therefore, within the teaching field, well-being has been described as "an individual sense of personal professional fulfilment, satisfaction, purposefulness, and happiness" (Soini et al., 2010, p. 741) which can be either strengthened or weakened by contextual factors and this fluctuation in return largely impacts the student's learning and well-being (Gray et al., 2017; Harding et al., 2019).

Well-being of Teachers during Disasters, Conflicts, and Pandemics

Research on teachers' motivation and well-being during conflicts or in conflict contexts like Lebanon is considered few. However, research on teachers' well-being during disasters showed that the mental health of people is connected to disasters and that mental instability, anxiety, emotional distress, lack of sleep, and depression are the most common symptoms teachers suffer from after disasters and crises (Makwana, 2019). Because crises and disasters are usually unpredictable, they put people in shock, in denial states and they make them more vulnerable to all the above (Peek, 2008). Berger et al. (2018) conducted a study to examine teachers' emotional well-being and their motivation at work after the Hazelwood mine fire events. The results of the study showed that the teachers encountered emotional problems such as frustration and weakness while teaching. Also, another study conducted by O'Toole and Friesen (2016) investigated how disasters influence teachers' emotional well-being and highlighted the necessity of providing teachers with adequate emotional support so that they could successfully cater to their students' emotional needs. Gray et al. (2017) illustrated in this regard that it is extremely important to understand the repercussions that can be imposed by disasters and traumatic events on teachers' wellness so that schools can be ready to overcome these consequences. Springer et al. (2006) argued that teachers' role is not limited to promoting academic development in the classroom, but they also act as counselors, mentors, and social workers in their communities. That is why O'Toole and Friesen (2016) emphasized that schools should give their teachers adequate emotional support to successfully cater to their students' emotional needs.

As for research done on teachers' well-being during the Covid-19 pandemic, it was evident that teachers' psychological health and well-being got affected negatively in many normal contexts so no wonder the situation might be harsher in conflict contexts. Atchan (2022) argued that teachers in Lebanon during the pandemic had to "deal with new obstacles such as remote instruction, social distancing, and technologically driven contact with students and parents, as well as school co-workers and administrators" during unprecedented and protracted crises (p. 17). All of this can increase the levels of anxiety and stress and can impact the teachers' well-being enormously (Ávalos et al., 2022). A research study conducted in Indonesia showed that a substantial percentage of teachers appreciated the new possibilities provided by online teaching, but still about 80% of the teachers were not satisfied. They were anxious and stressed because they felt insufficient and unconfident with the new mode of virtual teaching, which have hurt their well-being as stated by Fauzi and Khusuma (2020). Another study conducted by Alea et al. (2020) showed that many teachers in the Philippines did not have sufficient skills and expertise to run online instruction during the pandemic. Also, Gross and Opalka (2020) revealed that American teachers were not sufficiently supported and motivated during the pandemic, and this affected their motivation and well-being a lot. Similarly, in her article about teachers' wellbeing in Palestine, Nassar (2022) pointed out that the most challenging thing during the Covid-19 pandemic was maintaining the teachers' wellbeing and sanity in these highly demanding, unstable, and unsafe times. She emphasized that many teachers were "under pressure to plan, organize, care and teach under ambiguous situations while at the same time taking care of their own families" (Nassar, 2022, p. 27).

Therefore, according to the literature, which showed that teachers should be stress-free and happy at work to teach efficiently and effectively, it is sensible to say that the teachers' unpreparedness to work in unexpected working conditions whether during disasters, conflicts or pandemics will affect their well-being and efficacy. Thus, staying sane, enthusiastic, and motivated is a key factor in fostering quality learning outcomes (Lederman, 2020).

Methodology

This research study is undertaken to understand further the perceptions and the attitudes of the teachers working at schools in Lebanon during a time of crises, particularly after the eco-

conomic and financial crisis that started in 2019 and is still ongoing till the day of finishing this study in 2022. The interpretive paradigm was employed to explore the research questions about how different schoolteachers from both public and private schools find the impact of the current crises hitting Lebanon for three years on the education sector and what challenges are faced by them whether emotionally, psychologically, or materially. According to Creswell (2009), the interpretive paradigm “is directed at understanding phenomenon from an individual’s perspective, investigating interaction among individuals as well as the historical and cultural contexts which people inhabit” (p. 8). Therefore, to explore and understand teachers’ feelings and thoughts and the effect of the crises on their life and well-being, the interpretive paradigm which seeks to “clarify, understand and interpret the communication of speaking and acting subjects” is best employed (Cohen et al., 2007, p. 27). For this purpose, two types of online semi-structured interviews were conducted with 11 Lebanese teachers working either at private (7 teachers) or public (4 teachers) schools teaching at any grade level from kindergarten to grade 12 and aged between 25 and 50. The interviews in this study were conducted via Zoom calls (1 group online audio-visual interview with 3 teachers and 8 individual audio interviews). The online interviews helped in transcending the boundaries of time and space and reaching beyond the constraints of face-to-face contact (Salmons, 2014) which was deemed difficult during the time of conducting the study because of the Covid-19 pandemic and the turbulent situation in Lebanon. A convenience sampling technique was used for recruiting the interviewees and a saturation approach was pursued as both contracted and permanent fixed term public and private schoolteachers from different regions in Lebanon took part in this qualitative study. The participants were recruited via a popular social media group for teachers teaching in Lebanon. Wael, Maher, Rana, Ali, May, Aya, Fadia, Mona, Nadine, Hana, and Dana are the pseudonyms that were given for the 11 interviewees who willingly decided to take part in this study after seeing the announcement. Ethical issues were all taken into consideration in accordance with the University of Exeter Ethics framework such as participating in the study voluntarily, signing a detailed consent form, maintaining anonymity and confidentiality, and being told about the results of the study. The interviews were conducted online over a period of two months during the end of the academic year 2021-2022 in Arabic and then translated into English by the researcher.

The qualitative data of the online interviews were transcribed and analyzed thematically by adopting Braun and Clarke’s six phase thematic analysis framework (Braun & Clarke, 2006). Thematic analysis is deemed useful in this study because it helped in examining the perspectives of the different interviewees, highlighting the similarities and differences, and coming up with unexpected insights. The first two phases of this framework were carried out at the group interview with Wael, Maher, and Rana first to generate an initial list of codes. Then, I carried out the final four phases of the analysis by conducting online individual interviews based on the emergent themes. In the interviews, teachers reflected on their experiences in the schools they work at especially during these unprecedented times and voiced their concerns, challenges, and difficulties. They broke the silence and spoke about their life situations in their own words without shame or regret. However, one of the main challenges faced in this study was conducting the online group interview particularly because of power cuts and internet connectivity issues. The group interview was postponed twice to suit both the participants’ availability and the availability of electricity. Future face to face studies can be conducted about this topic with a bigger sample size to avoid such hurdles and generate more detailed results.

Findings and Discussions

From October 2019 to February 2021 most of the schools in Lebanon closed their doors for face-to-face learning because of various ongoing upheavals including the Covid-19 pandemic which made the situation even more critical. The study revealed that most of the schools, at the beginning of the crises, were worried about the shift to remote learning because “the shift required extra costs on behalf of the schools and the parents too” as one of the interviewees said. However, the pandemic necessitated the shift and pushed many prestigious private schools to

take the lead in this regard as the financial capability of their students' parents permitted them to do that. Therefore, it became obvious that schools in Lebanon were not all at the same pace during this critical period. Prestigious private schools adapted quickly and effectively to the new circumstances, moderate fee-paying and semi-free private schools took time to adjust whereas public schools suffered the most because neither the students and their parents nor the teachers and their administrations were ready for the shift. In these two academic years, all the students got promoted automatically to the next grade level without being asked to sit for final exams unlike normal times. This issue has caused a significant decrease in learning where students lost a year and a half of learning (Azevedo et al., 2021) and teachers struggled in mitigating the learning loss afterward. The current study is significant because it has shown that schoolteachers in Lebanon have been suffering just as the students and their parents since the very beginning of the crises in 2019. Interviews have revealed that teachers' income has declined massively due to hyperinflation and currency fluctuations and both private and public schoolteachers had to deal with new kinds of obstacles though less intense in the private educational sector as will be explained in detail below.

Schoolteachers' Experiences in the Last Three Academic Years (2019 till 2022)

Structural Constraints

During the first year of closures because of political upheaval in 2019, public schoolteachers were asked to teach remotely from home without being asked if they have access to the internet or not. The study revealed that most public schoolteachers did not have the internet at home, and they depended on 3G mainly on their mobile phones to deliver the lessons. Additionally, the other group of teachers who had internet services at home suffered from weak connectivity just like many of the people residing in Lebanon. A recent study has shown that the internet services started to decline in 2019 with the country's electricity crisis because the government opted to lower its financial assistance on fuel (Hammoud et al., 2021). This issue affected the country massively and caused long power cuts every day reaching 20 hours a day (World Bank, 2021). Moreover, it is not only most of the schoolteachers but also the students who suffered as well of serious network problems which made remote learning very frustrating to them and their parents. Aya, a primary public schoolteacher from the south of Lebanon, explained that public school students mostly do not have the internet at home, and many of them were borrowing 3G from their relatives and friends to attend their classes remotely. Also, she added that many of the parents with low educational attainment levels do not know how to use technology and many others are big in age with five or more children going to school all of whom needed devices and internet to attend remote classes daily. In the same regard, Dana stated that public school students come from poor socioeconomic backgrounds and "the whole environment is not suitable for remote learning at public schools regardless of how good and prepared the teachers are". On the other hand, teachers teaching at prestigious private schools explained that the situation was less difficult as their schools provided them with devices and internet to resume teaching from home, but the effort exerted was doubled as Maher and Rana affirmed because they were dealing with new types of challenges in addition to their daily teaching obligations.

Lack of Knowledge in Conducting Remote Learning

The study showed variations in readiness for remote learning. Public schoolteachers were asked to teach remotely without being prepared and the teachers had to figure out ways for doing that by themselves as Hana explained. As for public schoolteachers who teach at private schools as well found the shift a bit easier because most private schoolteachers were asked to sit for online training during the summer break of the academic year 2019-2020 although it was a bit late. That is why public schoolteachers' ability to do remote learning varied between the public schools and depended on each individual teacher. On the other side, prestigious private schoolteachers were ready from the beginning, but the moderate fee-paying private school-

teachers stated that the first year was very chaotic. Mona and Wael clarified in this regard that the students and the teachers were not trained to use online programs and when they started, the software used was not efficient, IDs were mixed up and teachers were mostly confused and experimenting most of the time.

The software did not work at the beginning... First, we used the Microsoft team, and after a few weeks we were asked to use google school, and every day we had a problem. New issues kept on coming up till things got settled in the first 2 months of the academic year 2020-2021. (Wael from the group interview).

Also, Mona said that all the logistics for remote learning created a problem for many private schoolteachers who were suffering from the repercussions of the socioeconomic crisis. They needed to purchase more things like additional laptops for the whole family, strong internet connections, an uninterruptible power supply in case there is no electricity and headphones to minimize the noise at home and allow others to work remotely as well. All of this have resulted in extra pressure on them, and their family members who had to find their own ways to sort this issue out. Noting that most of the private schools provided the staff with a laptop, but this process took a few months due to closures. Also, Ali who is a part-time secondary moderate fee-paying private schoolteacher said that in the academic year 2019-2020 their school was floundering, and the situation cannot be compared to 2020-2021 because the teachers were experimenting with the available systems to decide what to use. They were lost, and they taught via WhatsApp video calls, Zoom video calls, and some via YouTube videos. He emphasized that those teachers who managed to reach their students, succeeded not more than 50% in teaching them in 2019-2020, mainly because the students were not trained to shift to remote learning. In the same regard, Nadine, who is a private schoolteacher, said that she spent most of her time in front of the screen trying to figure out ways to teach virtually and she neglected unintentionally most of her duties toward her children and family members who were struggling as well. All of Nadine, May, Wael, Dana, May, Ali, and Mona who are private schoolteachers emphasized that remote learning pressurized them as teachers and affected their emotional and mental well-being greatly.

Security Constraints

Wael explained that during the first two years lots of security constraints affected the teachers' teaching plans. He said that nothing was predictable that year, "suddenly we hear there is a strike, and the roads get blocked immediately. We get stuck at school and our children get stuck at their schools. We are completely unsafe and worried about the situation". Also, another interviewee spoke about the instability faced during this period by saying:

If we say there is school tomorrow, some parents do not send their children and we had to postpone the lessons. We were always behind from repeating for those who missed classes because they could not reach school or because their parents were worried about sending them. Nothing went to plan which is why the school decided to give the parents the option of either sending their children to school or studying remotely. In fact, parents were controlling the school and the administration was pleasing them for tuition fees. (Dana from interview 2)

May as well said that she had to go through road closures and burning tires. She explained that she risked her life several times to avoid salary deductions and the students were her responsibility and she had to make sure they arrive and leave school safely. This situation was very stressful not only for May but also for most of the interviewees.

Mounting Stress and Frustration

As a result of this aggravated confusion in the country and the education sector, many parents who send their children to fee-paying private schools decided not to pay the tuition fees

for the first two academic years (2019-2020 and 2020-2021). This affected the teachers' salaries and caused many private schools to either reduce the salaries or lay some teachers off. Additionally, despite the depreciation of the Lebanese pound which almost lost 90 percent of its value, still many private and public schools pay teachers their salaries in the local currency. This issue affected teachers' ability to commute to and from school. Almost all the teachers interviewed stated that fuel prices have increased hugely, and they can no longer find petroleum easily. They need to line up for hours to fill their cars up. Ali said, "we are carpooling with our neighbours. One day I drop them to work and school. The next day my neighbours drop me and my children to school". Dana said "Thank God that I live close to work. It's a 15-minute walking distance but I still worry about finding fuel for windy or rainy weather". Wael, Maher and Rana all agreed that transportation prices have skyrocketed, and many teachers can no longer afford to travel to school with their peanut salaries. A contracted public schoolteacher said:

I get only what is equivalent to \$1 per hour, and I get paid twice or thrice per year. Can you imagine? How do they expect me to continue living in this country which requires paying for breathing fresh air or drinking clean water? (Aya from interview 6)

Also, Mona said that she is no longer buying new clothes because her current salary is worth a pair of shoes from Zara currently. Therefore, building on what has been said above by the interviewees, it has become clear that both public and moderate fee-paying private schoolteachers have been hard hit in the last three years and they feel unvalued and underpaid though with slight differences between the two educational sectors where public schoolteachers are hit the most. Second, come the moderate fee-paying private schoolteachers. As for prestigious private schoolteachers, they are still fine as they are still getting paid in dollars but the whole atmosphere in the country is depressing them all and affecting their well-being. If they need to travel, they need to wait for hours to fill the car with fuel. They depend on the government's electricity, private generators, and solar panels for securing energy. The water still cuts off during the day and life has completely changed. Medication became worse with limited medicines available when needed and only in big pharmacies in towns. It has become clear from the interviews that teachers are not happy. They have not only lost their status in the community but their dignity as a human. Many of them are suffering not only financially but also emotionally. Their well-being was impacted negatively, and they lost the motivation to work as many of the interviewees have explained.

I no longer feel I want to go to school. I am not happy at work. I am frustrated by everything happening around me. I thought Beirut Blast would be the worst thing ever, but it seemed it is not. What we are passing through currently from a tsunami of crises is beyond any comprehension and there is no hope for solutions on the horizon. (Ali from interview 7)

Fadia as well is a contracted public schoolteacher who expressed the same frustration. She explained that she is giving her students some stationaries despite her low wages, but she feels too bad when she finds a student not capable of having a pencil or an eraser to use in class. What the teachers are witnessing is a real deprivation as Wael, Maher and Rana said especially at public schools. Some children have a little amount of food to eat during recesses. They beg their teachers or friends to share with them their meal. Others come to school wearing ripped or dirty clothes. Education has become farfetched to many families because of the severe socio-economic situation and many public and moderate-fee private school children are dropping out of school very early to help their parents survive economically.

The Way Forward

Amidst all the crises that have occurred in the country lately, this study has shown that Lebanon's education system is not all right. It is suffering drastically, including both the public and the private system, though with slight changes depending on funding. Also, the teaching profession is no longer the reputable profession that used to be. Currently, it is causing stress and frustration to the teachers who have expressed their willingness to leave the profession and

find better opportunities either locally or abroad. These findings are very harsh for a country that was called the Mother of Laws during the Roman Empire and considered the pearl of the Middle East for decades and many visitors loved it and wished to live in it for its charm, educational institutions, cultural diversity, and natural beauty. Sadly, this country is in the opposite direction now with a broken economic and banking system, limited and weak public services and a declining education system jeopardizing the citizens' lives and the youth dreams with no clear turning point on the horizon. Hence, these findings necessitate policymakers in the MEHE to embark on a serious reform plan as soon as possible to save those who are left in the teaching profession, stop the brain drain and the exodus of many teachers by seriously tackling their challenges and difficulties. Also, the MEHE should address the growing learning crisis and meet the increased demand for online teaching at public schools as a result of the protracted crises by involving teachers in soft skills trainings, and online teaching trainings while maintaining the teachers' dignity and well-being to ensure equity and efficiency among all the schools and the students in Lebanon.

Biography

Tamara Al Khalili is a PhD candidate at the University of Exeter, an English teacher, and an English Arabic interpreter. Tamara taught English as a foreign language for several years in the MENA region and English preessional courses at the INTO University of Exeter. In her research record, Tamara has two research papers that cover different areas of education and foreign language teaching. Her research interests include writing instruction and assessment, foreign language challenges, equality in education, and educational reform and its effects on students, teachers, and the whole workforce in the educational institutions.

References

- Abdul-Hamid, H., & Yassine, M. (2020). *Political economy of education in Lebanon: Research for results program*. World Bank Publications.
- Akiri, A. A. (2014). Teachers' career satisfaction and students' academic performance in Delta Public Secondary Schools. *Journal of Educational and Social Research*, 4(1), 267.
- Akkary, R., & Greenfield, W. (1998). Leadership and Work Context of Public and Private Schools in the Republic of Lebanon. Annual Meeting of the American Educational Research Association, San Diego, California, April, (pp. 13-17)
- Amoli, F. A., & Youran, M. (2014). Delving the relationship between teacher empowerment and job satisfaction among Iranian EFL teachers in Tehran Aviation University. *Theory and Practice in Language Studies*, 4(4), 771.
- Ávalos, B., Flores, M. A., & Araneda, S. (2022). Battling to keep education going: Chilean and Portuguese teacher experiences in COVID-19 times. *Teachers and Teaching*, 28(2), 131-148.
- Avanzi, L., Miglioretti, M., Velasco, V., Balducci, C., Vecchio, L., Fraccaroli, F., & Skaalvik, E. M. (2013). Cross-validation of the Norwegian teacher's self-efficacy scale (NTSES). *Teaching and Teacher Education*, 31, 69-78.
- Azevedo, J. P., Hasan, A., Goldemberg, D., Geven, K., & Iqbal, S. A. (2021). Simulating the potential impacts of COVID-19 school closures on schooling and learning outcomes: A set of global estimates. *The World Bank Research Observer*, 36(1), 1-40.
- Bahou, L. (2017). 'Why do they make us feel like we're nothing? They are supposed to be teaching us to be something, to even surpass them!': Student (dis) engagement and public schooling in con-

- flict-affected Lebanon. *Cambridge Journal of Education*, 47(4), 493-512.
- Bahous, R., & Nabhani, M. (2008). Improving schools for social justice in Lebanon. *Improving Schools*, 11(2), 127-141.
- Bahous, R., Nabhani, M., & Cochran, J. (2011). Lebanon: Democracy based in religion. In J. Cochran, *Democracy in the Middle East: The impact of religion and education*, (pp. 135-154). Lanham: Lexington Books.
- Bogler, R., & Nir, A. E. (2012). The importance of teachers' perceived organizational support to job satisfaction: What's empowerment got to do with it? *Journal of Educational Administration*, 50(3), 287-306.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.
- Chamundeswari, S. (2013). Job satisfaction and performance of school teachers. *International Journal of Academic Research in Business and Social Sciences*, 3(5), 420.
- Chaudry, M., Sabir, H., Rafi, N., & Kalyar, M. (2011). Exploring the relationship between salary satisfaction and job satisfaction: A comparison of public and private sector organisations. *The Journal of Commerce*, 3(4), 1-14.
- Cohen, L., Manion, L., & Morrison, K. (2007). *Research methods in education* (sixth edit). Oxon: Routledge.
- Craddock, A. (2017). Education in Lebanon. World Education News and Review. In Credential Evaluation Issues, Education System Profiles, Middle East. Retrieved from <https://wenr.wes.org/2017/05/education-in-Lebanon>.
- Creswell, J. W. (2009). *Research design: Qualitative and mixed methods approaches*. London and Thousand Oaks: Sage Publications.
- Ghamrawi, N. (2010). No teacher left behind: Subject leadership that promotes teacher leadership. *Educational Management Administration & Leadership*, 38(3), 304-320.
- Gray, C., Wilcox, G., & Nordstokke, D. (2017). Teacher mental health, school climate, inclusive education and student learning: A review. *Canadian Psychology/Psychologie Canadienne*, 58(3), 203.
- Harding, S., Morris, R., Gunnell, D., Ford, T., Hollingworth, W., Tilling, K., Evans, R., Bell, S., Grey, J., & Brockman, R. (2019). Is teachers' mental health and wellbeing associated with students' mental health and wellbeing? *Journal of Affective Disorders*, 242, 180-187.
- Hammoud, M., Shuayb, M., & Al Samhoury, A. (2021). The Challenges and Prospects of Returning to School. Center for Lebanese Studies. Retrieved from [Digital-BTS-final.pdf \(lebanesestudies.com\)](#) Accessed 18, 8, 2022
- Ingersoll, R. M. (2001). Teacher turnover and teacher shortages: An organizational analysis. *American Educational Research Journal*, 38(3), 499-534.
- Lederman, D. (2020). Will shift to remote teaching be boon or bane for online learning. Inside higher Ed. Available from: <https://www.insidehighered.com/digital-learning/article/2020/03/18/most-teaching-going-remote-will-help-or-hurt-online-learning>
- Makwana, N. (2019). Disaster and its impact on mental health: A narrative review. *Journal of Family Medicine and Primary Care*, 8(10), 3090.
- Mattar, D. M. (2012). Factors affecting the performance of public schools in Lebanon. *International Journal of Educational Development*, 32(2), 252-263.
- Moghli, M. A., & Shuayb, M. (2020). Education under COVID-19 lockdown: Reflections from teachers, students & parents. *Center for Lebanese Studies, Lebanese American University: Beirut, Lebanon*.
- Najjar, D. (2009). *Effectiveness of management in private schools in Lebanon*. University of Birmingham.

- Nassar, S. (2022). Shifting to online education in schools in Palestine. *The Open Review Journal*, 7(4), 24-30.
- Pearson, L. C., & Moomaw, W. (2005). The relationship between teacher autonomy and stress, work satisfaction, empowerment, and professionalism. *Educational Research Quarterly*, 29(1), 38-54.
- Peek, L. (2008). Children and disasters: Understanding vulnerability, developing capacities, and promoting resilience-An introduction. *Children Youth and Environments*, 18(1), 1-29.
- Roffey, S. (2012). Pupil wellbeing-Teacher wellbeing: Two sides of the same coin? *Educational and Child Psychology*, 29(4), 8.
- Salmons, J. (2014). *Qualitative online interviews: Strategies, design, and skills*. Sage Publications.
- Shuayb, M. (2016). Education for social cohesion attempts in Lebanon: Reflections on the 1994 and 2010 education reforms. *Education as Change*, 20(3), 225-242.
- Skaalvik, E. M., & Skaalvik, S. (2010). Teacher self-efficacy and teacher burnout: A study of relations. *Teaching and Teacher Education*, 26(4), 1059-1069.

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SHORT ESSAY

Gender Disparity in Access to Higher Education: A Review of the Literature with Special Reference to the Omani Context

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Abstract

'Education for All' is the call of UN and its sub-organisation the United Nations Educational, Scientific and Cultural Organisation (UNESCO) that emphasises that education is a human right for all. However, access to education has been challenged with many obstacles, especially in higher education. One of these challenges is gender inequality, a significant factor that educational providers and policymakers must consider. This paper reviews pertinent literature to discuss higher education access and equality globally, and then sheds light on gender equality, with a special reference to the Omani context. The Omani experience with regard to access reflects gender disparity although statistics show that more female students are admitted to higher education institutions than males. This article questions the 50:50 admission policy that has resulted in admitting males with lower scores while depriving many eligible females of the very same opportunity. The article suggests investigating the causes behind this policy further and making amendments to ensure quality and good achievement in education by both genders and equality for access to HE.

Keywords: Higher Education, gender, disparity, Oman, access

Introduction

Education is undoubtedly a significant pillar that nations work on to improve and develop their society. Therefore, some international organisations such as the United Nations (UN) and its sub-organisation, the United Nations Educational, Scientific and Cultural Organisation (UNESCO), are calling for 'education for all' (EFA), which they view as a human right that countries must offer to their people (see, for example, UNESCO, 2017; Unterhalter, 2019; World Bank, 2018). However, there are many issues associated with education in general, as well as higher education (HE) in particular stated by many researchers. One of these concerns is the issue of access and equality that comes with an increasing number of students enrolling in higher education institutions (HEIs) (Acar, 1994; Archer, 2007; UNESCO, 2017; McLellan et al., 2016; Skelton et al., 2006). A large increase in the number of students enrolled in HEIs makes the issues of affordability and equality significant, thus affecting many students. Pertinent literature is reviewed, and the focus of this paper will be on one aspect of equality — gender equality — because it is currently viewed as an important factor that educational providers must consider (Skelton et al., 2006). More specifically, the paper explores female access to HE because gender equality has yet to be achieved in many contexts, and one of them is the Omani context that represents a serious disparity that needs to be addressed (Al'Omairi & Amzat, 2012; Kelly, 2009; Islam, 2014; Islam et al., 2017). This paper first discusses HE access and equality worldwide. It then moves on to gender equality in HE with a special reference to how Oman experiences gender disparity in its HEIs. The aim of this review is to discuss the influence of gender disparity in access to HE and the importance of reviewing access policies and make informed decisions to ensure access equality to HE.

Access and Equality in Higher Education

HE, as UNESCO (2017, p. 1) defined it, “builds on secondary education, providing learning activities in specialised fields of education. It provides learning at a high level of complexity and specialisation.” This type of education typically involves universities and colleges. Because HE is defined differently in various contexts and countries, this paper uses UNESCO's definition to refer to institutions, universities and colleges at a post-secondary level.

The world is developing rapidly in the current era of globalisation, with a growing need for well-educated people that can lead their respective countries. Notably, globalisation is a concept that is widely used to refer to the process in which social differences, national borders, cultures, customs and economies are dissolving (Hirst et al., 2009). Therefore, the fourth sustainable development goal (SDG4) set by the UNESCO aims at “ensur[ing] inclusive and equitable quality education and promot[ing] lifelong learning opportunities for all” by 2030 (UNESCO, 2019). Unterhalter (2019) also mentioned that through SDG4, the UNESCO aims to achieve their targets of providing all people in the world the right and opportunity to learn. To do so, it is the responsibility of national governments to sustain and develop conditions for every individual to be educated, regardless of their ethnicity, race, and gender, to achieve the desired outcomes (Unterhalter, 2006). The investment that each country continues via education in general and in HE is particularly vital. When a country invests in HEIs, it aims to develop human resources through providing a high-quality education that equips students with skills that the country requires to develop both socially and economically (Al-Lamki, 2002; Roudi-Fahimi & Moghadam, 2006).

Between 2000 and 2014, there was substantial growth in the ratio of enrolment to HE; “the number of students in higher education institutions more than doubled, rising from 100 million to 207 million” (UNESCO, 2017, p. 1). However, despite the wide and expanding access to HEIs, as reflected in UNESCO's report of 2017, there are disadvantaged groups of students in many countries (e.g. Southern African countries) that have not received their right to HE access. The term 'disadvantaged groups' has been broadly used in the literature to refer to female students, students with disabilities, as well as students from ethnic minorities and low social classes (see,

for example, Archer, 2007; Aikman et al., 2011; Delamont, 2006; McLellan et al., 2016; UNESCO, 2017; Unterhalter, 2006).

It is not expected that countries fully guarantee HE opportunities for every individual. However, there should be fair treatment for all the students when the same conditions exist, regardless of gender, ethnicity and other factors that socially under-represent people. It is asserted that segregation in access to and participation in HE remains for many students due to class, ethnicity and geography (McLellan et al., 2016). For instance, McLellan et al. (2016, p. 55) reported that in the UK, “Black and Asian students who do apply to the Russell Group [i.e. this is the group of elite universities in the UK] are much less likely to receive an offer than white and privately educated applicants with the same qualifications.” In addition, African and coloured students registered low enrolment rates in South Africa compared to whites (UNESCO, 2017). Also, the Ethiopian HE context is characterized by having such disparity and discrimination for particular population groups, “specifically women, geo-politically marginalized ethnic groups, people from low socioeconomic backgrounds and people from peripheral regional and rural areas. (Molla & Gale, 2015, p. 358). Although, as Molla and Gale (2015) elucidated, the Ethiopian Higher Education Proclamation stresses the fair distribution of HE, it is not practiced in reality, and gender disparity remains a serious issue. In other words, the expansion of HE does not reflect ‘equality of opportunity’ (McCowan, 2016). Instead, the aforementioned examples demonstrate that this opportunity is not truly given to disadvantaged groups in those countries and that disparity continues to exist despite UNESCO’s international goals and calls for parity in education. This scenario of inequality is also reflected in many other countries (see, for example, Balaska, 1994; King, 1998; McCowan, 2016; Thomas, 1990).

Furthermore, limitations of HE access can be due to financial issues. Al-Lamki (2002) explained that the high demands of HE result in financial constraints that a country might be unable to overcome. For this reason, in many countries, HE costs have been shifted from the government to other agents such as parents, students and private sector businesses. Johnstone (2004, p. 11) drew on this process of shifting costs as ‘revenue supplementation’. In most of Africa, Johnstone (2004) highlighted that the HE agenda was reformed with the introduction of cost-sharing. Highly qualified students are offered the opportunity for state-supported education, whereas those students who do not qualify for this opportunity can receive admission by paying tuition fees. In countries such as Australia, students are given income-contingent loans to pursue their HE, which they must repay once they are employed (Barr et al., 2019). In the UK, students must pay tuition fees because most courses have charged an annual fee of £9000 since 2012, leading to a reduction in the number of part-time students due to the increase in study fees (McLellan et al., 2016). However, in Oman, according to the National Centre for Statistics and Information (NCSI) (2018), the number of students enrolled in HEIs increased dramatically from 2006 to 2016 due to an increase in students being admitted to private colleges and institutions (see Appendix 1). In contrast to the UK, the number of students enrolling in self-supported/private HE programmes in Oman has been increasing because parents are willing to pay for the education of their children — which is one of the effects of globalisation (see, for example, Al-Issa, 2006; 2007). Another reason may be attributed to the annual internal and external scholarships that the Ministry of Higher Education (MoHE) offers at undergraduate and graduate levels (MoHE, 2019). Al-Issa (2006) pointed out that —in the era of globalisation— Omanis view HE as a gateway to finding white-collar jobs. However, this does not mean that everybody can afford to pay expensive tuition fees to obtain a degree without incurring loans, and there are groups of people who have not benefited from the policy of cost-sharing. As Barr et al. (2019) elucidated, receiving income-contingent loans can form a high burden on the low-earning borrowers who must repay the loans. Thus, due to financial barriers, students from low-income families may eventually decide not to enrol in HE to avoid this heavy repayment burden.

On the other hand, providing free HE might not attract students to enrol in HEIs. For instance, Balaska (1994) stated that although HE was free in Greece, there were still students

that did not aspire to have a degree because it was not a necessary qualification to obtain a job. However, as Balaska indicated, when the labour market demanded higher qualifications, parents and students were willing to invest in HE.

Higher Education and Gender Equality

As previously indicated, in addition to the financial and general social issues determining the access to and affordability of HE, gender can be a sociocultural factor that hinders access to HE, with women being considered as a disadvantaged group. This is because “gender is viewed as a multi-dimensional concept at the intersection of structured social divisions such as class, race, ethnicity and poverty” (Aikman et al., 2011). Therefore, the focus of the remainder of this paper will be on gender segregation because women are viewed as ‘newcomers to higher education’ in many countries and civilizations around the world (Delamont, 2006, p. 179) because women have not had the right to education until recently in a number of nations (see, for example, Kelly, 1984; Skelton et al., 2006; UNESCO, 2017).

The first university to officially admit women was Oberlin University in the USA in 1833 (Stiver & Malik, 1994), showing that before this time, women’s access to HE was rare or limited. This was because many societies were influenced by the views of Greek philosophers Aristotle and Plato regarding women as being inferior to men, not creative, not able to reach high levels of reasoning, and being defective compared to men (Balaska, 1994). Since the 1920s, women gradually began to fight for their right to education through the feminist movement (see, example, Balaska, 1994; Delamont, 2006; Skelton et al., 2006 for more information on feminism¹). Many changes occurred regarding the status of women due to feminism, particularly in HE, and women started receiving more services and freedom to practise their social and academic lives without parental restrictions than ever before (Delamont, 2006).

Today, many international organizations call for gender equality in education (see, for example, Al Sadi & Basit, 2017; Archer, 2007; Kelly, 2009; UNESCO, 2017). However, gender disparities do exist in all countries, with different degrees of inequality, and gender equality has not been achieved yet (Al Sadi & Basit, 2017). According to the UNESCO Institute for Statistics (2018), although countries attempt to eliminate gender inequalities, they persist in all levels of education, including HE, and disparity can be related to access in some countries or related to the specialisation choices of both genders. Although UNESCO (2017) encouraged providing equal opportunities for access to both genders because education is for all, it is stressed that the gap in rights between men and women remains substantial in Gulf countries (see, for example, Kelly, 2009). In addition, in countries such as Greece; although it is illegal to practise gender-based discrimination, traditional beliefs influence the Greek views towards women — even though university education is free (Balaska, 1994). Similarly, although there is no gender segregation in Pakistan, the number of female students is lower compared to their male counterparts, and women’s choices of HE courses are limited for the same reason — the traditional attitudes towards women’s roles in society and their own perceptions towards themselves and their abilities (Malik & Hussain, 1994). The influence of traditional beliefs exists despite universities having been established for women in Pakistan (UNESCO, 2017). In Turkey, Acar (1994) mentioned that gender-based differentiation and the number of female students is high in courses more ‘suitable’ for women (e.g., language and literature), which have weaker competition from male students and are less demanding. In Greece, the influence of social beliefs on women’s choices in HE is extended to the wage returns in work fields over-represented by women (e.g., humanities, education), and women receive the lowest wages, causing a gender-pay gap (Livanos & Pouliakas, 2012). This is beyond the scope of this paper.

1 Feminism is a term used to refer to the women’s movement to radically change their status in society and fight for rights they were not given, such as owning a property and going to school and university (Delamont, 2006).

This situation, where traditional attitudes have influence on women's choices, brings into question those social perceptions towards what the society believes is best for female students to choose so that their social status and obligations are not affected. The countries highlighted reflect some of the restrictions on the freedom of choice given to female students, which also calls the gender disparity of those countries into question. Although females may theoretically appear to be given the opportunity to choose the courses they want in HE, their choices are affected by social and cultural pressures that result in little space for freedom and an implicit gender-based disparity.

It is of paramount importance to mention that disparity between male and female students relates to both entering HEIs and completing degrees. According to UNESCO (2017), for every 100 female students entering HEIs in Costa Rica in 2014, 80 male students enrolled; however, only 55 males graduated. Similarly, in Western Asia and Northern Africa, the number of women graduating from higher education is more than that of men. This shows that the number of females entering HEIs is more than that of male students, and more females successfully graduate from HEIs than males. One might consider that females are not part of the 'disadvantaged group' anymore, and they are — to a large extent — obtaining their right to education in many places in the world, including Oman (highlighted in the following section). Are these statistics and numbers sufficient to reach the conclusion that disparity is eliminated and may not exist at all? The following section discusses this area with specific reference to the educational system in Oman and how female students are positioned in it to determine whether parity exists between genders. This is because in the Omani context, there is a lack of research highlighting the interrelationship between school performance, undergraduate level performance and gender parity — and to what extent policymakers consider these factors when establishing HEIs' admission policies (Islam, 2014).

Oman and Gender Equality in HE

Oman is a Muslim Arab country located in the Arabian Peninsula of the Middle East. Despite its numerous accomplishments and great Empire in Africa in the past, Oman was a 'closed book' with limited global interactions before 1970. When HM Sultan Qaboos (1970 $\frac{3}{4}$ 2020) came to power, numerous developmental changes occurred there. Notably, education was one of the primary goals of the Sultan because, before 1970, there were only three formal schools with 900 male students in them (Al-Ghanboosi, 2017; Al-Mahrooqi & Denman, 2018). Omani women were the most deprived women in the Gulf in terms of education and literacy because there were no schools for them during that period (Al-Sinani & Benn, 2011). When the Sultan began ruling the country, boys and girls were given equal priority to attend school. Furthermore, Oman's Basic Law of the State — declared in 1996 — guarantees and encourages gender equality (Donn & Issan, 2007). The number of schools for boys and girls has increased since 1970 to reach over 1000 schools to accommodate the growing population, which has reached over four million people (Al-Ghanboosi, 2017, NCSI, 2020).

Students who successfully finish their secondary education (16–18 years old) are given General Education Diploma (GED) certificates. To accommodate the large number of students with GEDs, public and private universities and colleges were established to offer various degrees and courses. The first public university is Sultan Qaboos University (SQU), which was established in 1986. It is worth noting that the GED is the only admission criterion for acceptance into HEIs in Oman. The focus of the rest of this paper will be on SQU because it is the most prestigious university that only admits secondary school students that achieved the highest grades. The registration and admission process for all HEIs is completed electronically through the Higher Education Admission Centre (HEAC), in which students register for their selected programmes and are allocated to different colleges and universities based on their GED grades (HEAC, 2022).

Over 34,000 students graduated with GEDs in the academic year 2017/2018 — 54.4% were females, and 45.6% were males (HEAC, 2019) (see Appendix 2). Based on these statistics, it is expected that more females than males were admitted to HEIs. Upon assessing official statistics on the ratio of males and females in HEIs in Oman, it might be assumed that females in Oman are more privileged than those women in other countries where female access to HE is restricted by traditional social views regarding the roles of women and their status and obligations in the society. According to the HEAC website (2019), 56.8% of students admitted to HEIs in 2018 in Oman were females. However, this does not mean that there is gender parity in Oman or that females are given more opportunities for access to HEIs than males. Because males generally score lower than females in school, some studies have shown that Oman aims for a 50:50 ratio of both genders in HEIs through admitting males with lower secondary school grades than females who are admitted to the same degrees and courses (see, for example, Al'Omaidri & Amzat, 2012; Kelly, 2009; Islam, 2014; Islam et al., 2017; Islam & Al-Ghassani, 2015).

In Oman and Kuwait, Kelly (2009) indicated that female students were required to obtain higher grade point averages (GPAs) than male students in order to be admitted to engineering courses. This disparity is described by university officers as 'reverse discrimination' which is "intended to increase the percentage of male students in certain academic fields." (Kelly, 2009, p. 5). Moreover, in a study conducted at SQU to investigate students' performance in the mathematics foundation course, it was found that females scored higher than males due to their high overall grades in GED and secondary school mathematics, subsequently influencing their performance at university (Islam et al., 2017). The study recruited 551 students taking the mathematics foundation course FPMT0105 in one semester. Data were obtained from the database of the Deanship of Admission and Registration at SQU. SPSS was used for statistical analysis. The researchers of this study highlighted that the average scores of females were between 80% and 97% in high secondary school, whereas they were between 56% and 96% for males. Also, they found that such performance in high secondary school affected their performance at the university. In other words, female students scored higher grades in the math course than males. In another similar study conducted at the same university, the average scores of male students were between 54% and 96%, and females scores ranged from 80% to 98% (Islam & Al-Ghassani, 2015). The researchers in both of these studies stressed that high secondary school scores are one of the primary reasons why males underperform compared to females at SQU (Islam et al., 2017). These studies also highlight a disparity in the admission of both genders to the university, resulting from the application of the 50:50 ratio policy. Moreover, the results of the two studies confirm the findings of Islam's (2014) research that investigated the factors influencing SQU students' academic performance. That study found that females' performance was better compared to males studying the same course (Islam, 2014). These findings are in line with another study that investigated 615 students who took Calculus I course in one semester (Islam & Al-Ghassani, 2015). Descriptive and inferential statistics were used to analyse students' scores. The performance of the target students in the study asserted that males were admitted to the university regardless of their weak performance in high secondary school and that their poor performance affected their academic achievement at university to a significant extent. However, this research only focused on students' scores in secondary school and at university. Moreover, they provided a highly limited scope of the factors that might influence the target students' performance. The strength of this study is that it focused on high secondary school performance, university performance and their relationship with gender. However other determinants such as the motivation level of the students and the socioeconomic status of their families may influence students' performance in addition to gender. The limited focus of these studies calls for large-scale qualitative analyses (e.g., interviews, observations) that can clearly interpret the quantitative data (e.g., test scores, overall grades) and more precisely evaluate the situation of Omani students by focusing on multiple factors. Qualitative data help to support and enrich quantitative data and also contribute to the credibility of the research (Tracy, 2010).

The admission of nearly equal numbers of male and female students at SQU (Islam et al., 2017) indicates that there are more eligible female students who should have been admitted to SQU than males. However, applying the 50:50 policy prevents many eligible females from obtaining access to SQU, resulting in them applying to other colleges and private universities that are socially viewed as less prestigious. Therefore, this issue puts the government admission policy into question. The admission policy reflects that females in Oman are underestimated and that this policy of admission may result in detrimental effects on the quality of education, females' and males' motivation to study, quality of graduates and the job market in the long run. When SQU students receive lower than grade C, for example, they are at risk of dropping out of the university or being placed under probation, subsequently lengthening their study duration (Islam & Al-Ghassani, 2015).

Although the government admits equal numbers of males and females, more males tend to drop out of college due to factors such as their low performance at university and low level of motivation (Islam, 2014). This observation confirms the UNESCO's (2017) findings that women are more likely to graduate and complete their courses than men. Thus, Islam and Al-Ghassani (2015) suggested that admission policies should be reviewed and reformed so that Omani students are equally given the right to compete for HE courses regardless of their gender. To make better admission decisions, it is also recommended that high secondary school results should not be taken as the only criterion of admission to HE (Islam & Al-Ghassani, 2015; Islam et al., 2017). For instance, SQU and other Omani HEIs may apply the experience of North America and other countries in having an admission test called the Scholastic Assessment Test (SAT), where students are offered admission based on their SAT and GED scores (Islam & Al-Ghassani, 2015). Moreover, Wan (2018) suggested having psychometric tests and interviews to reduce the emphasis on students' performance in high secondary school because it broadens the admission process.

It seems that via applying the 50:50 ratio policy in Oman — or what some researchers refer to as the 'discrimination policy' (see, for example, Donn & Issan, 2007) — gender equality means having equal numbers of both genders in HEIs. However, gender equality has not been achieved qualitatively or in terms of eligibility. This policy confirms Goodhart's Law, that states that when an indicator is used as a target, it may cease to be an effective measure and indicator (Mattson et al., 2021). Because the admissions policy uses numbers as an indicator of gender equality, it ceases to be a good indicator of equality. Measuring gender equality through HE admissions is a bad indicator of gender equality. A high GED score might be a blessing if it is obtained by a male because it guarantees admission easily for him; however, the same score for a girl cannot lead to her obtaining admission to a prestigious university. Practically speaking, this situation is a major dilemma, and it challenges the quality of the graduates because academic achievement at the undergraduate level is negatively affected by low GED grades. If gender was not considered, most of the students studying in HEIs would be females due to their outstanding GED performance, an issue that would eventually lead to females having most of the attractive jobs in the country because males do not generally achieve good GED scores. This is reflected in the data used in (Islam & Al-Ghassani, 2015; Islam et al., 2017) that indicate the high GED scores of females and their good performance in the math courses under investigation. Due to social beliefs and norms, males are financially responsible for their families in Oman. Therefore, male students need qualifications to obtain a job and be able to have families, whereas female students do not require qualifications to get married and have families.

Conclusions and Recommendations

To sum up, this paper aimed to review the literature related to gender disparity in HE and question the admission policy practiced in Oman as an example of an indirect practice of inequality that may cause negative effects in the long run. Gender inequality in HE can there-

fore be viewed as a significant issue that exists despite international efforts to eliminate it. It has been discussed that gender is a vital factor that governments must continue to address to ensure equality despite social and cultural values and beliefs that influence gender parity, such as indirectly causing female students to select certain courses over the others, thus limiting their freedom based on what the society wants them to do. In Oman, the issue of gender equality is complicated and presents a substantial dilemma. The government applies the 50:50 ratio admission policy, which provides opportunities for males to be admitted with lower scores while depriving many eligible females of the very same opportunity.

The 50:50 ratio policy is not a good measure of gender equality; it is an important indicator of gender inequality around which debates rise and point toward the plausible social, economic and academic interests behind it. Such interests need to be reviewed by policymakers and admission officers in order to predict the long-term consequences and outcomes of this policy. Therefore, it is suggested that the causes behind this policy are investigated further, and amendments are made to ensure quality and good achievement in education by both genders and equality for access to HE. In other words, to represent true parity in HE admissions, highly scoring females should not be deprived from admission for the sake of admitting more males, regardless of their scores. The causes of males scoring low grades in high secondary and later at university need to be investigated further. Also, other conditions can be introduced for admission into HEIs in addition to the GED scores to achieve parity in admission (e.g., entry tests or interviews).

Conflicting Interest

The author declared no potential conflicts of interest with respect to the research and/or publication of this article.

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References

- Acar, F. (1994). Higher education in Turkey: A gold bracelet for women. In S. Lie, L. Malik, & D. Harris (Eds.), *The gender gap in higher education* (pp. 160-170). London: Kogan Page Limited.
- Aikman, S., Halai, A., & Rubagiza, J. (2011). Conceptualising gender equality in research on education quality. *Comparative Education*, 47, 45–60
- Al-Ghanboosi, S. (2017). Oman: An overview. In S. Kirdar (Ed.), *Education in the Arab World* (pp. 157-178). UK and USA: Bloomsbury Academic.
- Al-Issa, A. (2006). The cultural and economic politics of English language teaching in Sultanate of Oman. *Asian EFL journal*, 8(1), 194-218.
- Al-Issa, A. (2007). The implications of implementing a 'flexible' syllabus for ESL policy in the

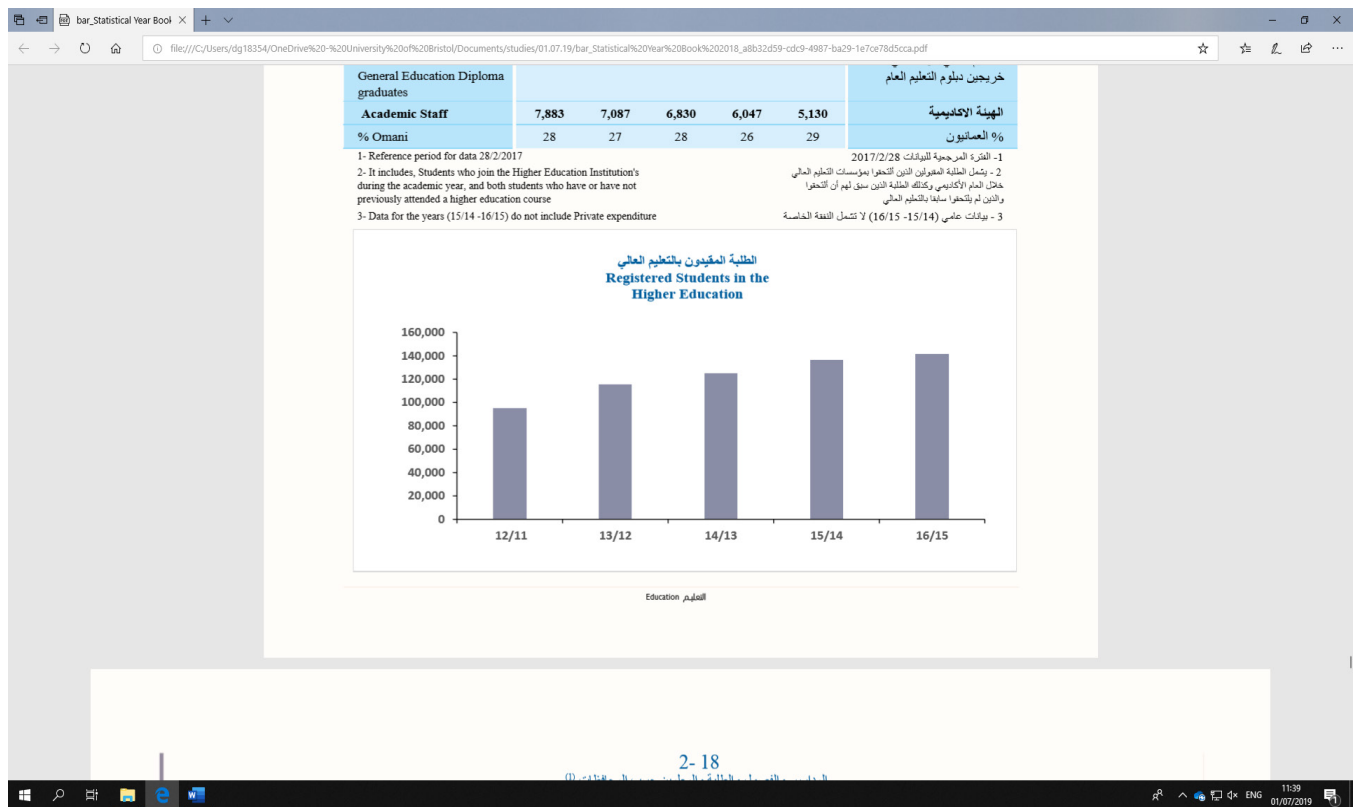
- Sultanate of Oman. *RELC Journal*, 38(1), 199-215.
- Al-Lamki, S. (2002). Higher education in the Sultanate of Oman: The challenge of access, equity and privatization. *Journal of Higher Education Policy and Management*, 24(1), 75-86.
- Al-Mahrooqi, M., & Denman, C. (2018). Introduction: English education in Oman: Current scenarios and future tragedies. In M. Al-Mahrooqi & C. Denman (Eds.), *English education in Oman: Current scenarios and future tragedies* (pp. 1-8). Springer.
- Al'Omairi, T., & Amzat, I. (2012). Women in Omani society: Education and participation. *OIDA International Journal of Sustainable Development*, 3(5), 63-80.
- Al Sadi, F. & Basit, T. (2017). Omani girls' conceptions of gender equality: addressing socially constructed sexist attitudes through educational intervention. *Oxford Review of Education*, 43(2), 209-224.
- Al-Sinani, Y., & Benn, T. (2011). The Sultanate of Oman and the position of girls and women in physical education and sport. *Muslim women and sport*, 125-137.
- Archer, L. (2007). Diversity, equality and higher education: A critical reflection on the ab/uses of equity discourse within widening participation. *Teaching in higher Education*, 12(5-6), 635-653.
- Balaska, J. (1994). 2,500 years after Plato: Greek women in higher education. In S. Lie, L. Malik, & D. Harris (Eds.), *The gender gap in higher education* (pp. 85-94). London: Kogan Page Limited.
- Barr, N., Chapman, B., Dearden, L., & Dynarski, S. (2019). The US college loans system: Lessons from Australia and England. *Economics of Education Review*, 71, 32-48.
- Delamont, S. (2006). Gender and higher education. In C. Skelton, B. Francis, & L. Smulyan (Eds.), *The SAGE handbook of gender and education* (pp. 179-189). SAGE Publications Ltd.
- Donn, G., & Issan, S. (2007). Higher education in transition: Gender and change in the Sultanate of Oman. *Scottish Educational Review*, 39(2), 173-185.
- HEAC. (2019). *Higher education admission statistics*. Ministry of Higher Education, Scientific Research and Innovation.
- HEAC. (2022). *Higher education admission statistics*. Ministry of Higher Education, Scientific Research and Innovation.
- Hirst, P., Thompson, G., & Bromley, S. (2009). *Globalization in Question*. Cambridge. Polity Press.
- Islam, M. (2014). Factors influencing the academic performance of undergraduate students in Sultan Qaboos University in Oman. *Journal of Emerging Trends in Educational Research and Policy Studies*, 5(4), 396-404.
- Islam, M., & Al-Ghassani, A. (2015). Predicting college math success: Do high school performance and gender matter? Evidence from Sultan Qaboos University in Oman. *International Journal of Higher Education*, 4(2), 67-80.
- Islam, M., Al-Ghassani, A., & Al-Hadhrami, A. (2017). An evaluation of the mathematics foundation course in Sultan Qaboos University: Does high school performance matter?. *Sultan Qaboos University Journal for Science [SQUJS]*, 22(2), 96-105.
- Johnstone, D. (2004). Higher education finance and accessibility: Tuition fees and student loans in sub-Saharan Africa. *Journal of higher education in Africa*, 2(2), 11-36.
- Kelly, G. (1984). Women's access to education in the Third World: myths and realities. In S. Acker, J. Megarry, S. Nisbet, & E. Hoyle (Eds.), *Women and Education* (pp. 81-89). London: Kogan Page Limited.
- Kelly, S. (2009). Recent gains and new opportunities for women's rights in the Gulf Arab states. *Women's Rights in the Middle East and North Africa: Gulf Edition*, 1-8.
- King, E. (1998). Entering higher education: Older students' constructions of self as learners. In J. Radford (Ed.), *Gender and choice in education and occupation* (pp. 84-103). London and New York: Routledge.

- Livanos, I., & Pouliakas, K. (2012). Educational segregation and the gender wage gap in Greece. *Journal of Economic Studies*, 39(5), 554-575.
- Malik, L., & Hussain, N. (1994). Women in higher education in Pakistan: separate but equal?. In S. Lie, L. Malik, & D. Harris (Eds.), *The gender gap in higher education* (pp. 129-138). London: Kogan Page Limited.
- Mattson, C., Bushardt, R., & Artino Jr, A. (2021). When a measure becomes a target, it ceases to be a good measure. *Journal of Graduate Medical Education*, 13(1), 2-5.
- McCowan, T. (2016). Three dimensions of equity of access to higher education. *Compare: A Journal of Comparative and International Education*, 46(4), 645-665.
- McLellan, J., Pettigrew, R., & Sperlinger, T. (2016). Remaking the elite university: An experiment in widening participation in the UK. *Power and education*, 8(1), 54-72.
- Ministry of Higher Education- Sultanate of Oman (MoHE). (2019). Retrieved from <https://mohe.gov.om/InnerPage.aspx?ID=eef41caf-2e19-4340-9389-5b246fdf24de&culture=en>
- Molla, T., & Gale, T. (2015). Inequality in Ethiopian higher education: Reframing the problem as capability deprivation. *Discourse: Studies in the Cultural Politics of Education*, 36(3), 383-397.
- NCSI. (2018). *Statistical Year Book 2018*. National Centre for Statistics and Information.
- NCSI. (2020). *Statistical Year Book 2020*. National Centre for Statistics and Information.
- Roudi-Fahimi, F., & Moghadam, V. (2006). Empowering women, developing society: Female education in the Middle East and North Africa. *Al-Raida Journal*, 4-11.
- Skelton, C, Francis, B., & Smulyan, L. (2006). Introduction. In C. Skelton, B. Francis, & L. Smulyan (Eds.), *The SAGE handbook of gender and education* (pp. 1-3). SAGE Publications Ltd.
- Stiver, S & Malik, L. (1994). Trends in the gender gap in higher education. In S. Lie, L. Malik, & D. Harris (Eds.), *The gender gap in higher education* (pp. 205-213). London: Kogan Page Limited.
- Thomas, K. (1990). *Gender and subject in higher education*. Buckingham: SRHE and Open University Press.
- Tracy, S. (2010). Qualitative Quality: Eight 'big-tent' criteria for excellent qualitative research. *Qualitative Inquiry*, 16(10), 837-851.
- UNESCO. (2017). *Six ways to ensure higher education leaves no one behind*. Paris: UNESCO.
- UNESCO. (2019). Retrieved from: <https://en.unesco.org/themes/education2030-sdg4>
- UNESCO Institute for Statistics. (2018). Retrieved from: <http://uis.unesco.org/en/news/international-womens-day-explore-latest-uis-data-eatlas-gender-inequality-education>
- Unterhalter, E. (2006). Gender, Education and Development. In C. Skelton, B. Francis, & L. Smulyan (Eds.), *The SAGE handbook of gender and education* (pp. 93-108). SAGE Publications Ltd.
- Unterhalter, E. (2019). The Many Meanings of Quality Education: Politics of Targets and Indicators in SDG 4. *Global Policy*, 10, 39-51.
- Wan, C. (2018). Student enrolment in Malaysian higher education: Is there gender disparity and what can we learn from the disparity?. *Compare: A Journal of Comparative and International Education*, 48(2), 244-261.

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Appendix 1

Registered students in HEIs in Oman (Source: NCSI, 2018, p. 404)²



Appendix 2

Graduates of GED in the academic year 2017/2018 (Source: HEAC, 2019, p. 21)

جدول (1-1) Table (1-1)
 خريجو دبلوم التعليم العام وما يعادله حسب نوع الشهادة والنوع للعام الدراسي 2018/2017م
 Graduates of the General Education Diploma and its equivalent according to the type of certificate and gender in the school year 2017/2018

Type of certificate	%	♂	♀	♂	نوع الشهادة
Grade12- Regular students	95.6%	33249	18297	14952	الثاني عشر - النظاميون
Grade12- Bilingual Schools	2.5%	875	367	508	الثاني عشر العام (المدارس ثنائية اللغة)
Grade12- Adult education	0.8%	266	183	83	الثاني عشر - دراسات حرة
Grade12 (Islamic Sciences Institutes)	0.5%	167	0	167	الثاني عشر (الادبي للعلوم الإسلامية)
International certificates	0.3%	96	37	59	شهادات دولية
General Education Diploma (Special Education)	0.2%	61	21	40	دبلوم التعليم العام (التربية الخاصة)
Grade12 (Royal Technical Guard)	0.1%	42	0	42	الثاني عشر التقني
Grade12 (Blind-regular students)	0.1%	18	7	11	الثاني عشر - مكفوفين نظامي
Special Education – Adult Education	0.0%	1	1	0	دبلوم التعليم العام (التربية الخاصة - تعليم الكبار)
Total	100%	34775	18913	15862	المجموع

2 X axis shows the number of the students. Y axis shows the academic years.

EXPLORING THE IMPACTS THAT VIRTUAL NATURE EXPOSURE CAN HAVE ON HEALTH AND WELL-BEING AND THE MECHANISMS INVOLVED:

A SYSTEMATIC REVIEW

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Abstract

Exposure to nature can improve health and well-being. However, numerous populations have restricted access to outdoor environments. Reviews show virtual nature exposure can provide benefits for a range of health and well-being outcomes. There is space for a systematic review that provides an overview of all outcomes impacted by virtual nature exposure, as well as underlying mechanisms. This systematic review searched databases; PsycINFO, MEDLINE, SCOPUS, Web of Science, and Google Scholar. Searches resulted in 9948 articles, with 66 studies included in the review. Findings showed virtual nature exposure can increase levels of mood, motivation, restorativeness, and cognitive functioning, whilst reducing anxiety, depressive symptoms, stress, and perceived pain. Presence and perceived restorativeness mediated improved positive affect after exposure, whilst connectedness to nature mediated improved positive affect and ability to reflect after exposure, and perceptions of safety mediated the extent to which enclosure of an environment predicted perceived restorativeness. There is support for virtual nature to be used in general and clinical settings for improving health and well-being, in addition as a tool for populations with limited mobility. Future studies should investigate long-term virtual exposure and conduct statistical analyses to understand the mechanisms linking virtual nature exposure with health and well-being outcomes.

I. INTRODUCTION

A. Natural environments

Exposure to natural environments can have numerous benefits for health and well-being, including reduced stress, increased positive affect (experiencing positive moods), and improved cognitive development (van den Berg *et al.*, 2018; McMahan & Estes, 2014; Maes *et al.*, 2021). Two theoretical frameworks underpin these impacts: *Attention Restoration Theory* (ART) (Kaplan & Kaplan, 1989), and *Stress Recovery Theory* (SRT) (Ulrich *et al.*, 1991). ART posits that exposure to a natural environment can be restorative, allowing directed attention to rest and recover, and restore from mental fatigue (Kaplan, 1995). Moreover, SRT states that exposure to natural elements can aid in recovery from stressful situations (Ulrich, 1981). Being in an unthreatening environment can activate a positive emotional response and sustain attention which in turn impedes negative emotions. These frameworks are well-known and have informed policies and practice.

There are policies with the aim to improve green space access, including considering local natural spaces as essential ways to maintain health and well-being, ensuring local policies are informed by evidence of the need for access, and prioritising access to green spaces for communities where access is deprived or unequal (Public Health England, 2020). However, many populations cannot access the outdoors. Roughly 56.2% of the global population live in cities and have fewer options for visiting local natural environments (Buchholz, 2020). Additionally, people may have access but avoid visiting due to lack of time, poor weather, or avoidance of unattractive features. Further, the COVID-19 pandemic has impacted the ability to go outdoors with enforced stay-at-home orders.

B. Immersive virtual environments

People can be exposed to natural environments without going outdoors, by using simulated alternatives such as images, videos, 360° videos, augmented, and virtual reality (VR). VR environments, otherwise known as Immersive Virtual Environments (IVEs), are commonly shown through head-mounted displays (HMDs) which block the vision of external reality and project a 360° virtual world. Virtual HMDs are more affordable and accessible for the public which allows IVEs to be viewed from home. Conversely, some argue that they require a fairly high level of computer proficiency which may instead make the technology less accessible (White *et al.*, 2018). One of the main downfalls of using IVEs is cybersickness. Consideration still needs to be taken regarding cybersickness and how this may instead hinder health.

C. Current literature reviews

The impact of virtual nature on attention restoration and affect have been explored in recent systematic reviews. One review and meta-analysis focused on attention restoration after exposure to real and simulated natural environments (Ohly *et al.*, 2016). Although informative through the synthesis of many study designs, it was difficult to conclude which types of simulations and populations benefited from attention restoration. Another review by Browning *et al.* (2021) focused on the methodological choices made by studies measuring health and cognitive outcomes after simulated nature, which included simulation methods, landscape features and controlled human factors. The review included all types of simulations. Furthermore, Browning *et al.* (2020a) compared the impacts of simulated nature and real nature on affect. They demonstrated that being outdoors in real natural settings is more beneficial for mood than viewing simulated natural environments, and that going outdoors should be favoured over being indoors. Overall, it is mostly agreed that the best form of exposure to nature is through real settings, however, VR can be used as an effective alternative if going outdoors is not feasible.

It is imperative to understand the pathways that explain the links. Pathways linking health

outcomes and being in urban green spaces have been outlined by the World Health Organisation (2016). These include improved relaxation and restoration; improved social capital; improved functioning of the immune system; enhanced physical activity, improved fitness, and reduced obesity; anthropogenic noise buffering and production of natural sounds; reduced exposure to air pollution; reduction of the urban heat island effect; enhanced pro-environmental behaviour; optimized exposure to sunlight; and improved sleep. However, the mechanisms linking outcomes and exposure to virtual nature are less understood.

D. Impact

A systematic review outlining how virtual nature has been used to impact health and well-being outcomes would be beneficial for all fields using virtual technologies and exposure to environments. A review outlining the mediators underlying virtual nature effects would be beneficial for informing practice and therapeutic interventions. Beneficial outcomes could encourage a new form of social prescribing, similar to 'green social prescribing' and prescriptions for nature exposure. It is also important to outline results which have shown negative effects and the underlying mediators. One can then advise individuals to avoid certain exposures or technology that may be detrimental to their health. Outcomes of exposure to simulations have been reported, however, they have been focused on individual outcomes, rather than broad overviews. Furthermore, reviews are predominantly quantitative including experimental designed studies (Ohly *et al.*, 2016; Browning *et al.*, 2020a). This leaves a gap for a review that encompasses both quantitative and qualitative, as well as all study designs. There is a need for the health and well-being outcomes from current studies to be presented in one paper. This reference paper would be an up-to-date overview of the field, providing a clear trajectory for how future research should be conducted.

E. Objectives

In this review, the health and well-being outcomes associated with virtual nature exposure are synthesized. There are two aims: firstly, to investigate which health and well-being outcomes can be affected by exposure to virtual nature, and secondly, to synthesis the mechanisms that explain why, and how, virtual nature can impact health and well-being. An overriding objective of this review is to bring together the vast literature surrounding the effects that virtual nature can have. Literature from the previous 21 years needs to be concisely displayed, alongside explanation of the mediators which underlie the published effects. These aims led to the following research questions:

RQ1: *“What are the impacts of virtual nature exposure on health and well-being?”*

RQ2: *“What are the mechanisms involved that underlie the effects on health and well-being gained from virtual nature exposure?”*

II. METHODS

This systematic review followed the guidelines for the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Moher *et al.*, 2009; Page *et al.*, 2021). Ethical approval was received from the University of Bath.

A. Eligibility criteria

Criteria for inclusion was any study whereby participants had exposure to virtual nature/natural environment. This included simulations such as 360° videos, VR, or augmented reality.

Still photographs, images, or pictures of natural environments were not included. Natural environments were any type of green or blue space and included biophilic elements. Studies using urban environments, or real environments, were included if a comparator condition to a natural virtual environment was used. The studies also needed to include at least one health or well-being outcome. The outcomes were kept broad (memory, attention, executive functioning, creativity, cognitive functioning). The most recent literature was searched from January 2000-July 2021. Sources needed to be written in English. Country of publication was not restricted. There was no restriction to populations studied; general or clinical. Quantitative and qualitative studies were included.

B. Information sources and search strategy

The databases searched were; PsycINFO, MEDLINE, SCOPUS, and Web of Science. All databases were last searched 27th July 2021. Grey literature was searched through the first 40 pages of Google Scholar. The first 40 pages were only searched due to the extensive results, lack of time available, and the lack of relevance in titles after the first 40 pages. Searches were conducted using three concepts: simulation strategies (e.g. simulation OR VR OR virtual etc), nature and natural environments as the exposure (e.g. green OR natur* OR “blue space” etc), and health and well-being measured outcomes (e.g. health OR well-being OR “mental health” etc). Search terms regarding mechanisms, pathways, and mediators were also included in the search strategy. Trial searches were conducted to identify if search terms were suitable and inform NOT terms.

C. Selection process

After database searches, results were exported into Mendeley reference manager and duplicates were removed. Title screening was then carried out by one researcher. If it was not apparent by the title whether the source was relevant, the abstract was screened, and a decision was made. After title screening, the full texts of relevant sources were screened. Relevant sources were included as the final studies in this review. A detailed data extraction form was populated for each study, and variables of importance were extracted, including; population, sample size, study design and comparators used, technology/type of simulation used, exposure/environment used, outcomes, main results, and information regarding mediators or causal pathways.

D. Quality assessment

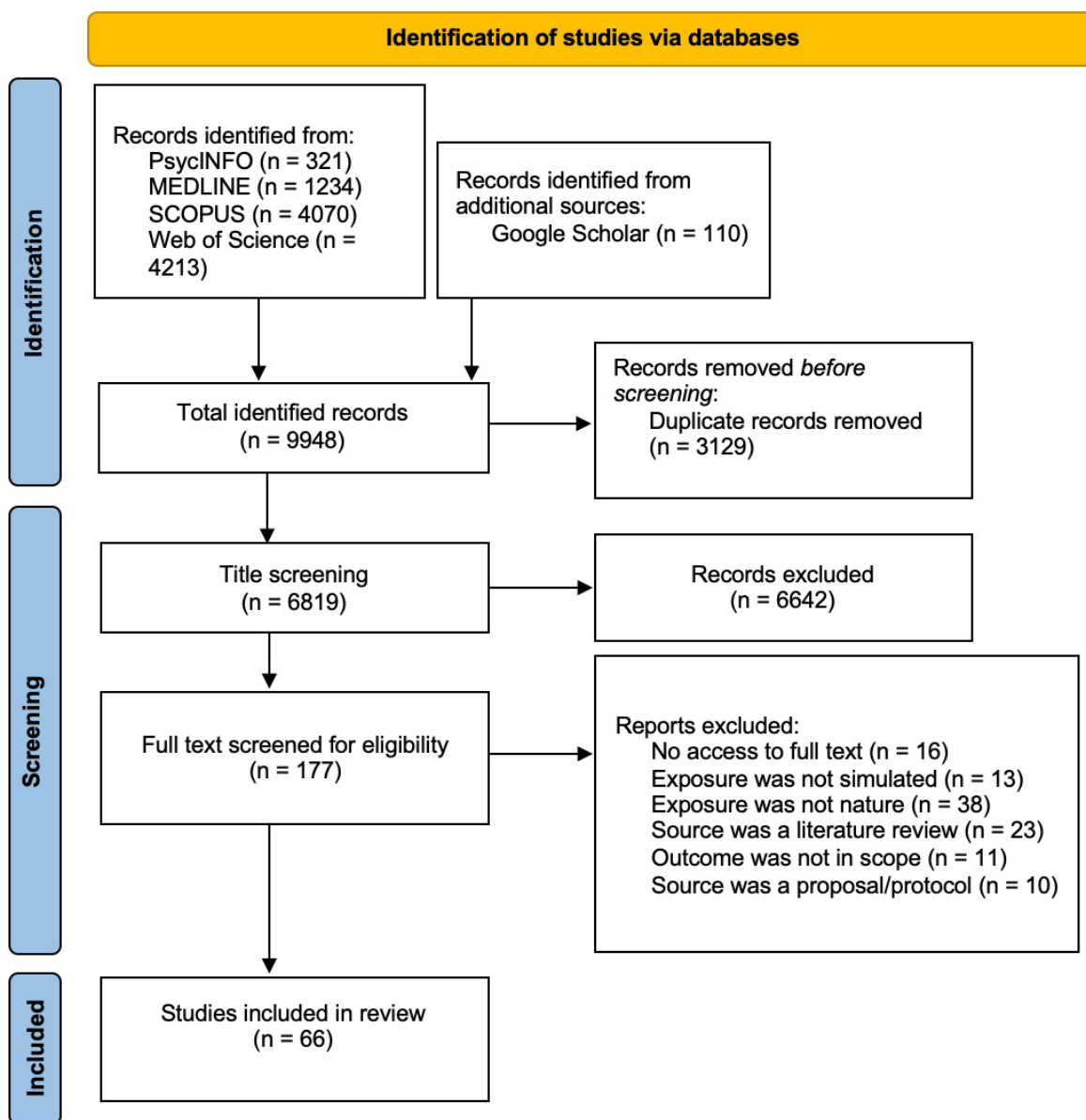
The Effective Public Health Practice Project's (EPHPP) Quality Assessment tool for Quantitative Studies (Thomas *et al.*, 2004) was used to assess the quality of the studies. The EPHPP rates studies on six components: selection bias, study design, controlling for confounders, blinding methods, data collection method, and withdrawals/dropouts. Each individual component section is rated as 'Strong', 'Moderate', or 'Weak', and a global rating is calculated. The quality assessments of studies were not used to exclude studies from this review, however, the quality assessment ratings given for each study were cautiously interpreted in the synthesis of results. The decision to not remove weakly rated studies was made so to capture results from a broad range of study designs.

III. RESULTS

A. Study selection

A total of 9948 records were sourced (Figure 1). After deduplication, a final 6819 sources went through title screening. 177 sources were eligible for full text screening which resulted in 66 individual studies included in this review. Reasons for exclusion whilst screening included: no access to full text, exposure was not simulated, exposure was not nature, outcome not in scope, or the source was a proposal or protocol. Literature reviews were excluded but are recognised in discussion with the results.

Figure 1. Flow-diagram based on Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.



B. General characteristics of sources

1. Locations and quality

No included studies had been conducted in low-middle income countries. Studies were predominantly conducted in the Global North, with the majority in Europe (Figure 2).

The studies were assessed for quality using the EPHPP. Most studies included in this review were assessed as being weak (Figure 2). Only some studies were considered as strong quality (6%). In sum, the general quality of the studies was poor and therefore the results should be interpreted with caution.

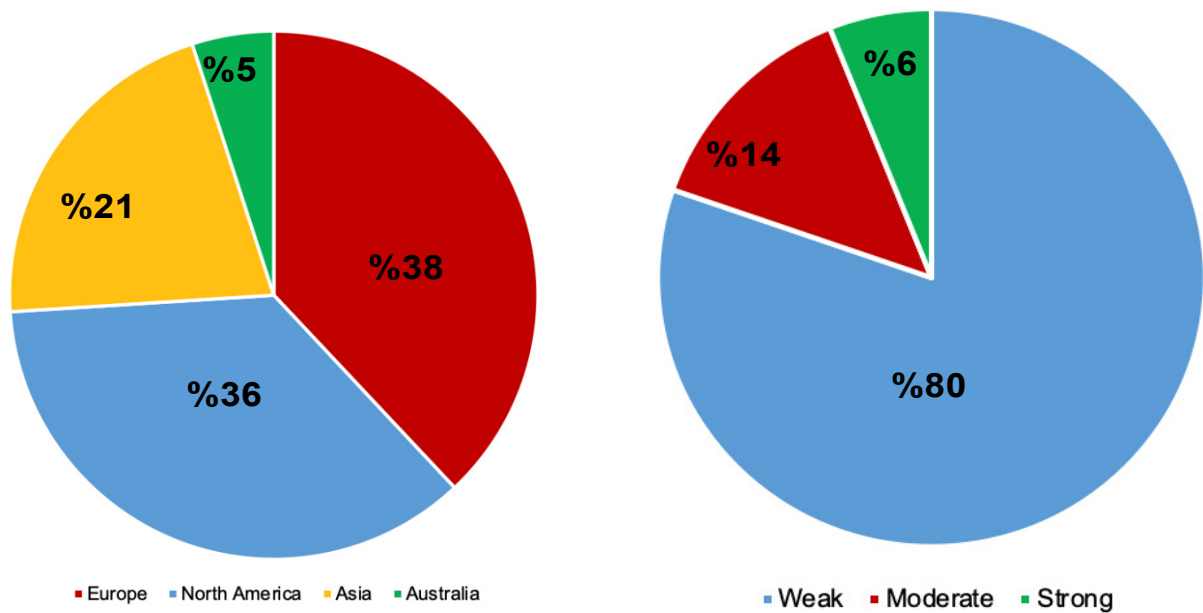
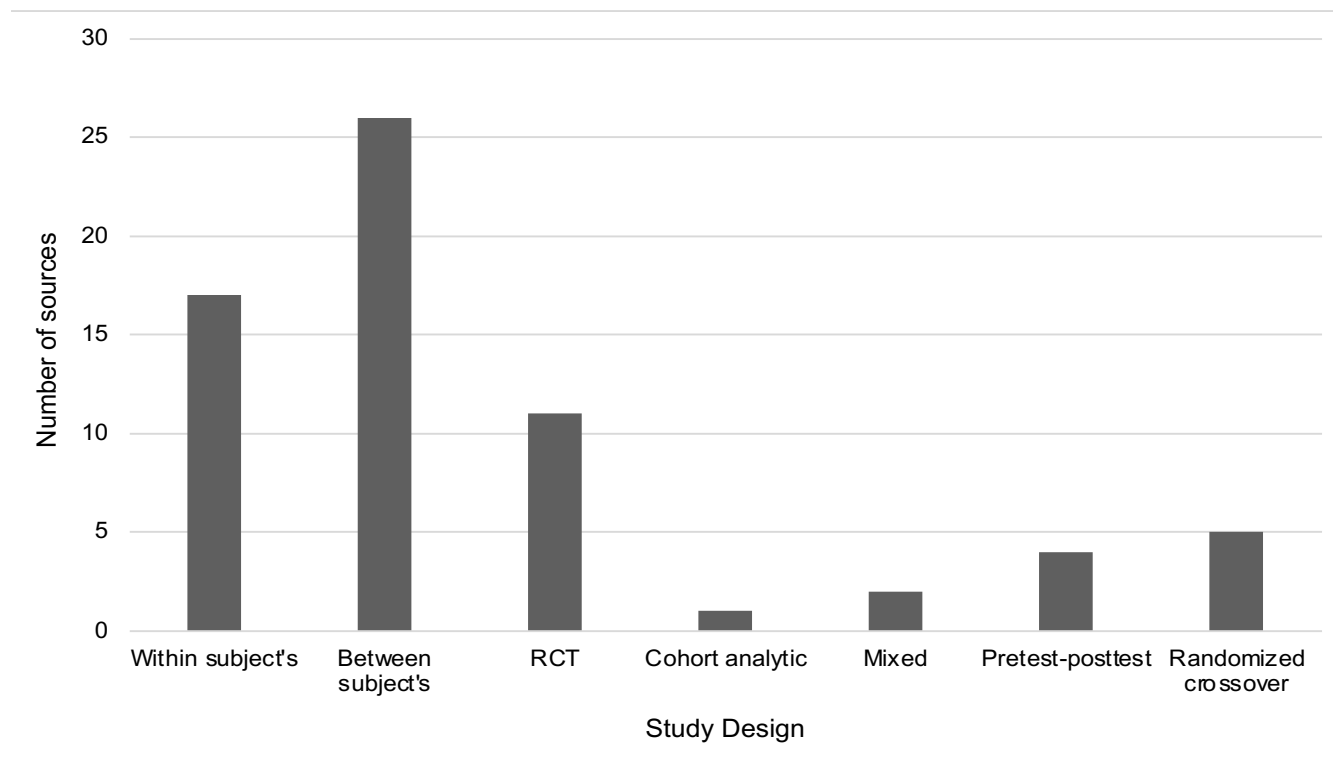


Figure 2. Pie charts showing the distribution of publication locations (left) and the quality of included studies (right).

2. Source type

Included studies were predominantly represented by between subject’s designs and RCTs (Figure 3). No study used solely qualitative methods.

Figure 3. Bar chart representing the study designs of included studies.



3. Samples

A broad range of populations and sample sizes were represented. The smallest sample size was 4 participants, and the largest was 444. The median sample size was 60. The studies broadly varied in ages of participants. Almost half of studies used an entirely adult (18+ yrs), non-student population or had a majority. Twenty-four studies consisted of university students, and five involved both university students and staff. One study involved a child population and five studies involved older adults or a sample where older adults (65+ years) were the majority.

4. Simulation

Thirty-five of the studies used VR HMDs as the simulation method. Five studies used VR glasses, one used VR goggles, and one used a VR viewer not requiring HMD. After VR HMDs, the second most commonly used simulation method was videos (excluding 360°) displayed as videotapes, on televisions, and on desktop computer screens. Two studies used 360° videos. Eight studies used projector screens. Two studies used a combination of methods (videos and VR HMDs). Duration of simulation varied. Most studies reported a simulation duration of 5 minutes or less. Twenty-two studies reported exposure length 6-10 minutes. Six studies reported 11-15 minutes, and three studies reported 16-20 minutes. Some studies had longer duration lengths; ten studies reported over 20 minutes. One study did not report duration length, and one study reported that participants were self-paced.

5. Nature exposure

A broad range of natural environments were represented. Most reported exposure to nature through scenes of forests, including woods, and bamboo forests. Seven studies used

natural elements in or outside buildings. Other environments included views of coastal paths/scenes, arboretums, gardens, parks, underwater scenes, and beaches. Most studies used several environment exposures. Five studies used a combination of scenes of beaches and green spaces. Eleven studies used scenes of multiple green spaces. These included open green spaces, gardens, walkways, nature reserves, meadows, hillsides, forests, mountains, parks, roadside vegetation, valleys, and tree canopies. Sixteen studies reported using 'nature scenes' which varied in green (forests, mountains, parks, trees, fields, nature island) and blue environments (bodies of water, riversides, streams, brooks).

C. Narrative synthesis - outcomes

Eight studies measured mood as an outcome and seven found beneficial impacts. Some examples are now described. One study investigated exposure to 360° videos and mood (Mostajeran *et al.*, 2021). Viewing a forest helped decrease feelings of fatigue, and mood was more disturbed by urban environment exposure. Gao *et al.* (2019) measured mood before and after virtual nature exposure. They found an alleviation in negative mood after exposure, but positive mood did not significantly improve. Wang *et al.* (2020a) exposed a positive association between positive mood scores and a neat undergrowth landscape of the forest. Additionally, positive mood effects have been found after exposure to indoor environments with biophilic elements (Yin *et al.*, 2018). Positive effects have also been found in prison populations (Nadkarni *et al.*, 2021). Incarcerated men felt less anxious and depressed, and calmer after viewing nature videos. Similarly, chemotherapy patients have been found to feel more relaxed, calmer, and more content after viewing VR nature scenes (Wilson & Scorsone, 2021).

Affect after virtual nature exposure was also measured. For example, positive affective states increased after viewing a virtual natural landscape (Reese *et al.*, 2021). Valtchanov *et al.* (2010) found increased positive affect after using VR. Two studies also found increases in positive affect after participants viewed videotapes of an arboretum, compared to an urban environment (Mayer *et al.*, 2009). However, this positive impact was more substantial after exposure to a real natural environment. Some studies measured levels of affect in participants with depressive symptoms after viewing a forest and a built environment video on a computer (Meuwese *et al.*, 2021). Viewing the forest video reduced negative affect for participants with depressive symptoms, compared to viewing the built environment. McAllister *et al.* (2017) found increased positive affect and decreased negative affect after viewing a nature video compared to no nature. Calogiuri *et al.* (2018) measured affect after participants experienced a real nature walk and a virtual comparison. Increased affect was associated with the nature walk, whereas poorer affect was associated with the virtual environment. Calogiuri *et al.* (2018) attributed this to cyber sickness.

Other studies measured self-reported and physiologically measured anxiety. Wang *et al.* (2020) found that patients with generalized anxiety disorder (GAD) showed lower galvanic skin responses (a physiological indicator of stress), after exposure to a virtual nature environment, compared to a control. Further, Zabini *et al.* (2020) measured perceived anxiety after exposure to a virtual forest compared to an urban environment. Short term effects for reduced anxiety were seen for those exposed to the virtual forest environment.

Several studies measured multiple outcomes. For example, depressive symptoms of older women were lowered after participation in a group-based programme involving viewing a virtual therapeutic garden (Szczepanska-Gieracha *et al.*, 2021). Browning *et al.* (2020) found being outdoors in a natural environment and viewing a 360° VR video of nature proved beneficial for increasing arousal and positive moods compared to an indoor environment without nature. One study focused on state social motivation whereby participants experiencing virtual nature

exposure, compared to controls, reported higher levels of state social motivation (Castelblanco, 2019). Further, Anderson *et al.* (2017) found reductions in negative affect after VR exposure to natural settings. When comparing 2D nature to VR simulated, participants reported greater levels of positive affect and satisfaction when viewing VR nature (Frewen *et al.*, 2020). Also, when viewing an underwater environment on a computer screen compared to VR, lower levels of anxiety are observed for VR, whereas there is a decline in positive affect for computer screen (Liszio *et al.*, 2018). Moreover, one study measured affect and boredom of participants during exposure to nature through three simulations: 2D video on HD TV, 360-degree VR HMD, or computer-generated VR (Yeo *et al.*, 2020). Negative affect and boredom levels reduced, and positive affect increased across all conditions.

Some studies measured stress and/or relaxation. One study found that virtual nature stimuli evoked a decrease in stress levels in incarcerated individuals (Nadkarni *et al.*, 2021). Further, participants reported lower levels of self-reported stress after a VR nature experience (Reese *et al.*, 2021). Another found that viewing VR nature can also be a distraction at work and significantly reduce GSR and heart rate (Ahmaniemi *et al.*, 2017). Kim *et al.* (2017) found that higher levels of perceived tranquillity were shown after exposure to environments with more pastoral (quiet, not urban) features. Further, Kim and Lee (2018) reported higher levels of calmness after exposure to a virtual nature environment, compared to an urban or indoor environment. In addition to these studies, other research focuses on restoration from stress after virtual nature exposure (Yin *et al.*, 2020; Yin, 2019; Valtchanov *et al.*, 2010; Schebella *et al.*, 2020; Meuwese *et al.*, 2021; Wang *et al.*, 2019a; Hedblom *et al.*, 2019; Li *et al.*, 2020; Liszio *et al.*, 2018; De Kort *et al.*, 2006).

Two studies found virtual nature to act as a buffer against stress. Chan *et al.* (2021) investigated exposure to virtual vertical greenery and found that exposure prevented stress, whereas Blum *et al.* (2019) found that viewing virtual nature to implement immersive heart rate variability biofeedback acted as a buffer to stress compared to a non-VR condition. But some studies found different results. Snell *et al.* (2019) measured recovery from stress after viewing a perceived live video of nature, a recorded video or control. The results showed stress recovery was similar for the perceived live and recorded video conditions. Further, when compared to 360° videos, photos of urban and forest environments were more effective in reducing stress (Mostajeran *et al.*, 2021).

Additionally, six studies focused on attention capabilities after virtual nature. Crosson and Salmoni (2021) found significant improvements in directed attention performance after viewing a forest on a 180° projector screen whilst walking on a treadmill. Another study found positive restorative effects on attentional fatigue when viewing natural spaces with VR glasses (Gao *et al.*, 2019). A further two studies showed attentional capacity and the ability to reflect increased for participants viewing a natural environment (Mayer *et al.*, 2009). Snell *et al.* (2019) measured attention recovery and reported improvements on the Necker Cube Pattern Control task after watching a perceived live video of nature compared to a recorded and control video. One study found significant results with cognitive performance (Mostajeran *et al.*, 2021). Participants made fewer errors on a cognitive task after viewing a virtual forest compared to an urban area. Three studies measured creativity as an outcome; scores on a creativity test improved after viewing virtual indoor office environments with biophilic features environments (Yin *et al.*, 2019).

Self-reported restorativeness was a common outcome. One study involved looking at levels of self-reported presence after viewing virtual nature (Chung, 2018). Participants scoring higher in self-reported presence perceived the environment as more restorative. Further, Chung *et al.* (2018) showed a negative association between restorativeness scores and fronto-central region P3a amplitudes, a biomarker of attention, after virtual nature exposure. Three studies compared perceived restoration after virtual nature exposure. Virtual nature was rated as more restorative than virtual urban environments (Yu *et al.*, 2020), and this was similar for adults on

an ICU (Gerber *et al.*, 2019). Similarly, McAllister *et al.* (2017) found greater perceived restorativeness after viewing wild nature and urban nature videos. Two studies compared exposure to virtual and real forests (Mattila *et al.*, 2020; Browning *et al.*, 2020). In Mattila *et al.*'s (2020) study, perceived restorativeness was the same after viewing a virtual forest and being in a physical forest. Similarly, Browning *et al.* (2020) found that participants rated virtual and physical nature exposure as both being restorative, compared to an indoor control. Finally, Wang *et al.* (2020) reported increased levels of restorative quality when viewing virtual nature, whereas Tabrizian *et al.* (2018) found that restorativeness was inversely affected by the spatial arrangement and permeability of the park setting.

Finally, some studies measured walking function in clinical populations after exposure to VR natural environments. Walking ability improved after VR nature exposure (Biffi *et al.*, 2015; Cho *et al.*, 2015). Additionally, pain and exertion were outcomes of some studies. Perceived and experienced levels of pain improved after virtual nature exposure (Gromala *et al.*, 2015; Tanja-Dijkstra *et al.*, 2018), and higher levels of exertion after a virtual nature experience were recorded (Calogiuri *et al.*, 2018).

D. Mediators

Overall, five mediators and one moderator were statistically analysed and found to be significant. These included:

- Presence as a mediator for improved positive affect after virtual nature exposure ($p < 0.01$) (Yeo *et al.*, 2020).
- Presence as a mediator for virtual experiences and emotions ($p < 0.05$) (Riva *et al.*, 2007).
- Perceived restorativeness as a mediator for improved positive affect after virtual nature exposure ($p < 0.001$) (McAllister *et al.*, 2017).
- Connectedness to nature as a mediator for improved positive affect and ability to reflect after virtual nature exposure ($p < 0.001$) (Mayer *et al.*, 2009).
- Perceptions of safety as a mediator for the extent to which enclosure of environment predicts perceived restorativeness ($p < 0.001$) (Tabrizian *et al.*, 2018).
- Depressive symptoms as a moderator for increased stress reduction after virtual nature exposure ($p < 0.001$) (Meuwese *et al.*, 2021).

IV. DISCUSSION

A. Summary and interpretation

This paper systematically reviewed the literature on the impacts that exposure to virtual nature can have on health and well-being, and aimed to answer two research questions: “What are the impacts of virtual nature exposure on health and well-being?”, and “What are the mechanisms involved that underlie the effects on health and well-being gained from virtual nature exposure?”

The results support that virtual exposure to natural environments could be particularly useful for improving health and well-being for people who cannot access outdoor environments, which supports White *et al.*'s hypothesis (2018). Virtual nature can act as a practical way to deliver a therapeutic intervention without over-exerting patients or exposing them to the risk of allergic reactions or accidental injuries (Jennings *et al.*, 2019). Prison populations were also

highlighted in this review, showing that virtual nature can be an alternative for those in long-term confinement. After all, the environment and experience of prison is very influential on prisoner's ability to rehabilitate afterwards (Söderlund & Newman, 2017). However, physical biophilic elements, such as indoor potted plants, can also be beneficial for health (Nieuwenhuis *et al.*, 2014) and this would be a more cost-effective option to implement in prisons and health care facilities. The results of this review are not consistent with Browning *et al.*'s (2020a) meta-analyses, which showed that being outdoors in a real setting provides more benefits to mood than viewing a simulated virtual setting. Meta-analyses are a strong analysis method which provide objective and generalisable results, however Browning *et al.* (2020a) only included experimental data in their review. This may be why the results are inconsistent.

This review also briefly identified five mediators and one moderator that were statistically analysed by some included studies, answering research question 2. Presence was found to be a mediator of improved positive affect after virtual nature exposure, as well as for general virtual experiences and emotions. Presence refers to the feeling of experiencing an illusion of being in a virtual environment without knowing for sure whether you are there (Slater, 2018). Feeling present and in the illusion of the virtual environment can lead to improved positive affect. Perceived restorativeness was also found to be a mediator for improved positive affect. This finding was in line with ART (Kaplan & Kaplan, 1989) and supports a link between restoration and virtual nature. When viewing a natural environment, the extent to which enclosure and feelings of being enclosed predicted perceived restorativeness was mediated by perceptions of safety. Previous literature shows that open space is key as to whether an environment is perceived as safe (Loewen *et al.*, 1993).

The mechanisms described by WHO (2016) are mostly different to the mechanisms regarding virtual nature and health and well-being outcomes presented here. Although one similar mechanism refers to increased restoration and restorativeness can mediate the increases seen in positive affect after exposure to real and virtual natural environments. There are some suggestions for the differences. Firstly, several mechanisms reported by WHO (2016) relate to being physically outdoors. It is likely that these were not found as mechanisms specific to virtual nature due to them not being recognised outcomes with being indoors. Some studies in this review did combine physical activity on treadmills whilst viewing virtual nature (Biffi *et al.*, 2015; Cho *et al.*, 2015), however they did not conduct mediation analyses.

B. Limitations

One limitation was that no studies were conducted in low-middle income countries. This may be due to the development of immersive technologies in predominantly high-income countries. But it is essential to know whether virtual nature can have an impact in low-middle income countries, especially as these countries have limited mental health services (Saxena & Maulik, 2003). Another limitation is that only short-term effects of virtual nature exposure were investigated. Many of the studies only used one short dose of virtual exposure. Whilst it is important to understand the short-term impact, if health care practices and therapeutic interventions are going to use virtual exposure as a tool, it is essential to investigate long-term exposure. Furthermore, limited studies conducted mediation or moderation analyses. This highlights the lack of research that has provided an explanation through a mechanism/pathway and provides little structure for practice/policies to use.

The methodology of this review also has limitations. The majority of studies were rated as 'weak' in quality, and so should be interpreted with caution. Although the aim was to provide an overview of the various study designs that have been used, this means that the methods used are not fully reliable. In addition, whilst qualitative studies were searched for, none were eligible for this review. There is a gap to investigate qualitatively how different populations experience virtual nature exposure.

C. Implications

It is imperative that future research incorporates mediation analyses into their methodologies, so to explain the links between health and well-being outcomes and virtual nature exposure. There may be more mechanisms that explain outcomes which are known due to the lack of analyses conducted. Also, future research needs to qualitatively investigate the same field. Researchers could understand more about how participants think/feel whilst experiencing virtual nature. This review can be improved by following a more rigorous methodology and presenting a statistical synthesis of results and formally assess trustworthiness of results reported in included studies. Furthermore, there are new methods in health care practices that involve 'green social prescribing' (NHS, 2021). Virtual nature could follow a similar trajectory, and if consistently found to be beneficial for patients with limited mobility, it has potential to become a prescription for mental health. This research has further importance in relation to the recent COVID-19 pandemic when stay-at-home orders were enforced. Virtual nature exposure could be especially helpful in these situations, and similar, when access to real environments is limited.

V. CONCLUSION

There is extensive support for exposure to nature being beneficial for health and well-being, and some studies advocate real nature as irreplaceable exposure. However, literature is showing virtual nature exposure to be a beneficial alternative exposure for populations with limited mobility. This review presented studies which have shown beneficial impacts on a broad range of outcomes. This synthesis has shown potential to use virtual nature exposure in general settings, as well as clinical and therapeutic interventions. Immersive technologies can be integrated into a range of settings where they can be used to benefit physical and mental health. But some studies have shown no impact or negative impacts of virtual exposure namely due to the risks of technology usage (e.g. cybersickness) which should be taken into consideration. Furthermore, caution should be taken with extensive use of these technologies as long-term impact is unknown. This review provides a beginning for future studies to investigate the long-term effects of exposure, and the underlying mechanisms. This could inform policy and allow for these technological methods to be used to their optimum in improving health and well-being.

REFERENCES

- Ahmaniemi, T., Lindholm, H., Muller, K., & Taipalus, T. (2017). Virtual Reality Experience as a Stress Recovery Solution in Workplace. *IEEE Life Sciences Conference (LSC)*. 2017-January, 206-209.
- Anderson, A., Fellows, A.M., Cowan, D.R., & Buckley, J.C. (2017). Relaxation with Immersive Natural Scenes Presented Using Virtual Reality. *Aerospace Medicine and Human Performance*. 88(6), 520-526.
- Biffi, E., Beretta, E., Diella, E., Panzeri, D., Turconi, A.C., Strazzer, S., et al (2015). Gait rehabilitation with a high tech platform based on virtual reality conveys improvements in walking ability of children suffering from acquired brain injury. *Annu Int Conf IEEE Eng Med Biol Soc*. 7406-9.
- Blum, J., Rockstroh, C., & Göritz, A. S. (2019). Heart rate variability biofeedback based on slow-paced breathing with immersive virtual reality nature scenery. *Frontiers in Psychology*, 10, 2172.
- Browning, M.H., Saeidi-Rizi, F., McAnirlin, O., Yoon, H., & Pei, Y. (2021). The Role of Methodological Choices in the Effects of Experimental Exposure to Simulated Natural Landscapes on Human Health and Cognitive Performances: A Systematic Review. *Environment and Behavior*. 53(7), 687-731.
- Browning, M.H., Mimnaugh, K. J., van Riper, C. J., Laurent, H. K., & LaValle, S. M. (2020). Can simulated nature support mental health? Comparing short, single-doses of 360-degree nature videos in virtual reality with the outdoors. *Frontiers in psychology*, 10, 2667.

- Browning, M.H., Shipley, N., McAnirlin, O., Becker, D., Yu, C.P., Hartig, T., et al. (2020a). An actual natural setting improves mood better than its virtual counterpart: A meta-analysis of experimental data. *Frontiers in psychology*. 11, 2200.
- Buchholz, K. (2020). How has the world's urban population changed from 1950 to today? *World Economic Forum*. Retrieved from: <https://www.weforum.org/agenda/2020/11/global-continent-urban-population-urbanisation-percent/> [Accessed 10 September 2021].
- Calogiuri, G., Litleskare, S., Fagerheim, K. A., Rydgren, T. L., Brambilla, E., & Thurston, M. (2018). Experiencing nature through immersive virtual environments: Environmental perceptions, physical engagement, and affective responses during a simulated nature walk. *Frontiers in psychology*, 8, 2321.
- Castelblanco, S. A. (2021). The Effects of Virtual Nature Exposure on State Social Motivation. *Electronic Theses and Dissertations*. Paper 3860.
- Chan, S.H.M., Qiu, L., Esposito, G., & Mai, K.P. (2021). Vertical greenery buffers against stress: Evidence from psychophysiological responses in virtual reality. *Landscape and Urban Planning*. 213(104127).
- Cho, K.H., Kim, M.K., Lee, H-J., & Lee, W.H. (2015). Virtual Reality Training with Cognitive Load Improves Walking Function in Chronic Stroke Patients. *Tohoku J. Exp. Med*. 236, 273-280.
- Chung, K. (2018). *MMN/P3a complex: A distinct event-related potential (ERP) biomarker of involuntary attention restoration during exposure to virtual nature in healthy adults*. Available from: Research Gate.
- Crossan, C., & Salmoni, A. (2021). A Simulated Walk in Nature: Testing Predictions From the Attention Restoration Theory. *Environment and Behaviour*. 53(3), 277-295.
- De Kort, Y.A.W., Meijnders, A.L., Sponselee, A.A.G., & IJsselsteijn, W.A. (2006). What's wrong with virtual trees? Restoring from stress in a mediated environment. *Journal of Environmental Psychology*. 26, 309-320.
- Frewen, P., Mistry, D., Zhu, J., Kiehl, T., Wekerle, C., Lanius, R. A., et al (2020). Proof of concept of an eclectic, integrative therapeutic approach to mental health and well-being through virtual reality technology. *Frontiers in Psychology*. 11, 858.
- Gao, T., Zhang, T., Zhu, L., Gao, Y., & Qiu, L. (2019). Exploring Psychophysiological Restoration and Individual Preference in the Different Environments Based on Virtual Reality. *International Journal of Environmental Research and Public Health*. 16, 3102.
- Gerber, S. M., Jeitziner, M. M., Sängler, S. D., Knobel, S. E., Marchal-Crespo, L., Muri, R. M., et al. (2019). Comparing the relaxing effects of different virtual reality environments in the intensive care unit: observational study. *JMIR perioperative medicine*. 2(2), e15579.
- Gromala, D., Tong, X., Choo, A., Karamnejad, M., & Shaw, C. D. (2015, April). The virtual meditative walk: virtual reality therapy for chronic pain management. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems* (pp. 521-524).
- Hedblom, M., Gunnarsson, B., Iravani, B., Knez, I., Schaefer, M., Thorsson, P., & Lundström, J. N. (2019). Reduction of physiological stress by urban green space in a multisensory virtual experiment. *Scientific reports*. 9(1), 1-11.
- Jennings, V., Browning, M.H.E.M., & Rigolon, A. (2019). Friend or Foe? An Overview of the Services and Disservices from Urban Green Spaces. In: *Urban Green Spaces*. SpringerBriefs in Geography. Springer Cham.
- Jiang, B., He, J., Chen, J., Larsen, L., & Wang, H. (2021). Perceived Green at Speed: A Simulated Driving Experiment Raises New Questions for Attention Restoration Theory and Stress Reduction Theory. *Environment and Behavior*. 53(3), 296-335.
- Kaplan, S. (1995). The restorative benefits of nature: Toward an integrative framework. *Journal of Environmental Psychology*. 15 169-182.
- Kaplan, R., & Kaplan, S. (1989). *The experience of nature: A psychological perspective*. Cambridge University Press, New York.
- Kim, J., Kil, N., Holland, S., & Middleton, W. K. (2017). The effect of visual and auditory coherence on

- perceptions of tranquility after simulated nature experiences. *Ecopsychology*. 9(3), 182-189.
- Kim, T., & Lee, S. (2018, February). Restorative Effects of Exercise in Virtual Environments. In *Proceedings of the 9th Augmented Human International Conference* (pp. 1-3).
- Li, C., Sun, C., Sun, M., Yuan, Y., & Li, P. (2020). Effects of brightness levels on stress recovery when viewing a virtual reality forest with simulated natural light. *Urban Forestry & Urban Greening*. 56. 126865.
- Liszio, S., Graf, L., & Masuch, M. (2018). The Relaxing Effect of Virtual Nature: Immersive Technology Provides Relief in Acute Stress Situations. In B.K. Wiederhold, G. Riva, and S. Bouchard (Eds.), *Annual Review of Cyber Therapy and Telemedicine* (pp. 87-93). USA: Interactive Media Institute.
- Loewen, L.J., Steel, G.D., & Suedfeld, P. (1993). Perceived safety from crime in the urban environment. *Journal of Environmental Psychology*. 13(4), 323-331.
- Maes, M.J., Pirani, M., Booth, E.R., Shen, C., Milligan, B., Jones, K.E., et al. (2021). Benefit of woodland and other natural environments for adolescents' cognition and mental health. *Nature Sustainability*. 1-8.
- Mattila, O., Korhonen, A., Pöyry, E., Hauru, K., Holopainen, J., & Parvinen, P. (2020). Restoration in a virtual reality forest environment. *Computers in Human Behavior*. 107, 106295.
- Mayer, F.S., McPherson Frantz, C., Bruehlman-Senecal, E., & Dolliver, K. (2009). Why is Nature Beneficial? The Role of Connectedness to Nature. *Environment and Behavior*. 41(5), 607-643.
- McAllister, E., Bhullar, N., & Schutte, N.S. (2017). Into the Woods or a Stroll in the Park: How Virtual Contact with Nature Impacts Positive and Negative Affect. *International Journal of Environmental Research and Public Health*. 14, 786.
- Meuwese, D., Dijkstra, K., Maas, J., & Koole, S.L. (2021). Beating the blues by viewing Green: Depressive symptoms predict greater restoration from stress and negative affect after viewing a nature video. *Journal of Environmental Psychology*. 75, 101594.
- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D.G. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *British Medical Journal*. 339, b2535.
- Mostajeran, F., Krzikawski, J., Steinicke, F., & Kühn, S. (2021). Effects of exposure to immersive videos and photo slideshows of forest and urban environments. *Scientific Reports*. 11(1), 1-14.
- Nadkarni, N.M., Thys, T.M., Ruff, J.S., Anholt, A., Treviño, J., & Yeo, S.K. (2021). Providing Virtual Nature Experiences to Incarcerated Men Reduces Stress and Increases Interest in the Environment. *Ecopsychology*. 13(2), 71-83.
- National Health Service (NHS). (2021). *Green social prescribing*. Retrieved from: <https://www.england.nhs.uk/personalisedcare/social-prescribing/green-social-prescribing/> [Accessed 10 September 2021].
- Nieuwenhuis, M., Knight, C., Postmes, T., & Haslam, S.A. (2014). The relative benefits of green versus lean office space: Three field experiments. *Journal of Experimental Psychology: Applied*. 20, 199-214.
- Ohly, H., White, M.P., Wheeler, B.W., Bethel, A., Ukoumunne, O.C., Nikolaou, V., et al. (2016). Attention Restoration Theory: A systematic review of the attention restoration potential of exposure to natural environments. *Journal of Toxicology and Environmental Health*. Part B, 19(7), 305-343.
- Page, M.J., McKenzie, J.E., Bossuyt, P.M., Boutron, I., Hoffmann, T.C., Mulrow, C.D., et al. (2021). The PRISMA statement: an updated guideline for reporting systematic reviews. *BMJ*. 372(71).
- Public Health England (2020). *Improving access to greenspace. A new review for 2020*. Public Health England. Retrieved from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/904439/Improving_access_to_greenspace_2020_review.pdf [Accessed 23 August 2021].
- Reese, G., Kohler, E., & Menzel, C. (2021). Restore or Get Restored: The Effect of Control on Stress Reduction and Restoration in Virtual Nature Settings. *Sustainability*. 13, 1995.
- Reynolds, L., Rogers, O., Benford, A., Ingwaldson, A., Vu, B., Holstege, T., et al. (2020). Virtual Nature as an Intervention for Reducing Stress and Improving Mood in People with Substance Use Disorder.

Journal of Addiction. 2020, 1892390.

- Riva, G., Mantovani, F., Capideville, C. S., Preziosa, A., Morganti, F., Villani, D., et al. (2007). Affective interactions using virtual reality: the link between presence and emotions. *Cyberpsychology & behavior*. 10(1), 45-56.
- Saxena, S., & Maulik, P.K. (2003). Mental health services in low- and middle-income countries: an overview. *Current Opinion in Psychiatry*. 16(4), 437-442.
- Scates, D., Dickinson, J.I., Sullivan, K., Cline, H., & Balaraman, R. (2020). Using Nature-Inspired Virtual Reality as a Distraction to Reduce Stress and Pain Among Cancer Patients. *Environment and Behaviour*. 52(8), 895-918.
- Schebella, M.F., Weber, D., Schultz, L., & Weinstein, P. (2019). The Nature of Reality: Human Stress Recovery during Exposure to Biodiverse, Multisensory Virtual Environments. *International Journal of Environmental Research and Public Health*. 17, 56.
- Sjölander, A., Ung, E.J., Theorell, T., Nilsson, A., & Ung, K-A. (2019). Hospital Design with Nature Films Reduces Stress-Related Variables in Patients Undergoing Colonoscopy. *Health Environments Research & Design Journal*. 12(4), 186-196.
- Slater, M. (2018). Immersion and the illusion of presence in virtual reality. *British Journal of Psychology*. 109, 431-433.
- Snell, T.L., McLean, L.A., McAsey, F., Zhang, M., & Maggs, D. (2019). Nature Streaming: Contrasting the Effectiveness of Perceived Live and Recorded Videos of Nature for Restoration. *Environment and Behavior*. 51(9-10), 1082-1105.
- Söderlund, J., & Newman, P. (2017). Improving Mental Health in Prisons Through Biophilic Design. *The Prison Journal*. 97(6), 750-772.
- Szczepńska-Gieracha, J., Cieślik, B., Serweta, A., & Klajs, K. (2021). Virtual Therapeutic Garden: A Promising Method Supporting the Treatment of Depressive Symptoms in Late-Life: A Randomized Pilot Study. *Journal of Clinical Medicine*. 10, 1942.
- Tabrizian, P., Baran, P.K., Smith, W.R., & Meentemeyer, R.K. (2018). Exploring perceived restoration potential of urban green enclosure through immersive virtual environments. *Journal of Environmental Psychology*. 55, 99-109.
- Tanja-Dijkstra, K., Pahl, S., White, M.P., Auvray, M., Stone, R.J., Andrade, J., et al. (2018). The Soothing Sea: A Virtual Coastal Walk Can Reduce Experienced and Recollected Pain. *Environment and Behavior*. 50(6), 599-625.
- Thomas, B.H., Ciliska, D., Dobbins, M., & Micucci, S. (2004). A process for systematically reviewing the literature: Providing the research evidence for public health nursing interventions. *Worldviews on Evid Based Nurs*. 1(3), 176-184.
- Ulrich, R.S. (1981). Natural versus urban scenes: Some psychophysiological effects. *Environment and Behavior*. 13, 523-556.
- Van den Berg, A.E., Joye, Y., & de Vries, S. (2018). Health benefits of Nature. In: Steg, L., de Groot, J.I.M. (Eds) *Environmental Psychology: An Introduction*. (pp. 55-64) Wiley.
- Valtchanov, D., Barton, K.R., & Ellard, C. (2010). Restorative Effects of Virtual Nature Settings. *Cyberpsychology, Behaviour, and Social Networking*. 13(5).
- Wang, X., Shi, Y., Zhang, B., & Chiang, Y. (2019a). The Influence of Forest Resting Environments on Stress Using Virtual Reality. *International Journal of Environmental Research and Public Health*. 16, 3263.
- Wang, T-C., Sit, C. H-P., Tang, T-W., & Tsai, C-L. (2020). Psychological and Physiological Responses in Patients with Generalized Anxiety Disorder: The Use of Acute Exercise and Virtual Reality Environment. *International Journal of Environmental Research and Public Health*. 17, 4855.
- Wang, Y., Jiang, M., Huang, Y., Sheng, Z., Huang, X., Lin, W., et al. (2020a). Physiological and Psychological Effects of Watching Videos of Different Durations Showing Urban Bamboo Forests with Varied Structures. *International Journal of Environmental Research and Public Health*. 17, 3434.
- White, M.P., Yeo, N.L., Vassilijev, P., Lundstedt, R., Wallergård, M., Albin, M., & Löhmus, M. (2018). A

- prescription for “nature” – the potential of using virtual nature in therapeutics. *Neuropsychiatric disease and treatment*. 14, 3001-3013.
- Wilson, K., & Scorsone, G. (2021). The Use of Virtual Reality Technologies to Reduce Anxiety and Improve Experience in Chemotherapy Patients During Treatment. *Frontiers in Virtual Reality*. 2, 88.
- World Health Organization. (2016). *Urban green spaces and health. A review of evidence*. Copenhagen: WHO European Regional office. Available from: https://www.euro.who.int/_data/assets/pdf_file/0005/321971/Urban-green-spaces-and-health-review-evidence.pdf [Accessed 11 August 2021].
- Yeo, N.L., White, M.P., Alcock, I., Garside, R., Dean, S.G., Smalley, A.J., et al. (2020). What is the best way of delivering virtual nature for improving mood? An experimental comparison of high definition TV, 360 video, and computer generated virtual reality. *Journal of Environmental Psychology*. 72, 101500.
- Yin, J. (2019). *Bringing Nature Indoors with Virtual Reality: Human Responses to Biophilic Design in Buildings* (Doctoral dissertation, Harvard University).
- Yin, J., Zhu, S., MacNaughton, P., Allen, J.G., & Spengler, J.D. (2018). Physiological and cognitive performance of exposure to biophilic indoor environment. *Building and Environment*. 132, 255-262.
- Yin, J., Arfaei, N., MacNaughton, P., Catalano, P. J., Allen, J. G., & Spengler, J. D. (2019). Effects of biophilic interventions in office on stress reaction and cognitive function: A randomized crossover study in virtual reality. *Indoor Air*. 29(6), 1028-1039.
- Yin, J., Yuan, J., Arfarei, N., Catalano, P.J., Allen, J.G., & Spengler, J.D. (2020). Effects of biophilic indoor environment on stress and anxiety recovery: A between-subjects experiment in virtual reality. *Environment International*. 136, 105427.
- Yu, C-P., Lee, H-Y., Lu, W-H., Huang, Y-C., & Browning, M.H.E.M. (2020). Restorative effects of virtual natural settings on middle-aged and elderly adults. *Urban Forestry & Urban Greening*. 56, 126863.
- Zabini, F., Albanese, L., Becheri, F.R., Gavazzi, G., Giganti, F., Giovanelli, F., et al. (2020). Comparative Study of the Restorative Effects of Forest and Urban Videos during COVID-19 Lockdown: Intrinsic and Benchmark Values. *International Journal of Environmental Research and Public Health*. 17, 8011.

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Environmental identity: being curious and confident in nature.

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What is environmental identity

There is no clear definition of environmental identity, which is also dependent on the disciplinary lens used to show what, when, where, who, and the places and spaces that shape the child's relationship with the natural world. Blatt (2013) suggests a socio-cultural influence informs a sense of social environmental identity such as educational background and context (forest school or classroom setting), individual background, and social interactions. For example, does the child perceive themselves connected to nature or in a separate human-made environment. Building on the above, Clayton and Opatow (2003) suggest environmental identity is defined by social construction and understanding the self and others' interaction with the natural environment. It includes how people feel about the natural world through emotional connections and intrinsic value, and how people think about inherent values of the natural world. Similarly, Stapleton (2015) reflects on social components that frame environmental identity as opposed to nature-based theories. So, perhaps as humans, social construct is a start point to understand environmental identity. The next section explores the influences that give meaning to environmental identity.

There are three approaches that influence environmental identity in early child development and life-long learning as an adult. Without getting entangled in the myriad of environmental identity measurement scales, which all differ, I want to focus on the thinking, feeling, and doing that shape and embody environmental identity. The first consideration about environmental identity is being in nature. This could be a local park, community garden or blue and green spaces such as the coast and woodlands. Secondly, Balunde et al. (2019), and Clayton and Opatow (2003) suggest contact with nature is important to us as well as to who we are and may lead to identifying with environmental-friendly behaviours such as reduce, recycle, repair, and reuse (Greenpeace, 2015) or supporting climate actions, campaigns, and causes as a type of personal green agency. In critique, I wonder if the opposite of a child having no contact with the natural

world could cause a disconnect, and lead to ambivalent and pessimistic attitudes about nature. In reflection, the above generalisations about how environmental identity is shaped could be viewed as a continuum of perception influenced by individual and collective experience. For example, a group leader reflects on the inter-connection between people and nature, adding 'we don't know if we are organising communities to plant trees or planting trees to organise communities' (Clayton, 2003, p. 91).

Another perspective used by children to make sense of nature and their environmental identity is anthropomorphism. Tam et al. (2013) argues giving nature and wildlife human attributes such as characteristics, emotions, and names can help children to feel connected to nature. For example, terminology such as Mr Nature, Mother Earth, Benny Bee, Sammy the Seahawk, and Tommy twig can spark the child's curiosity to know more about nature, and the child's place in the natural world. Anthropomorphism also applies to domestic pets such as 'that is a funny cat', and 'this is a clever dog'. Waytz et al. (2010) suggest the determinants for children using anthropomorphism is not fully understood but in doing so, children are able to make inductive inference from what they see and experience in the non-human world. Gebhard et al. (2003) suggest children keep anthropomorphic reasoning up to the age of about 12 years. However, from the ages of 12 – 16 years, stronger societal views may override how children relate to nature, which in western society might include a greater focus on personal interest and gains. The positive effect of anthropomorphism is argued by Waytz et al. (2010) who adds, anthropomorphism provides a sense of belonging from an inter-relational connection with nature, when social contact is not possible through experiences of poorly mental health or physical health. Secondly, Waytz et al. (2010) suggest a connection to nature could reduce anxiety, depression, and isolation through enhanced efficacy to feel better and lift mood by being part of a wider system of life. Additionally, Tam et al. (2013) argue anthropomorphism is a low-cost strategy to promote environmental concepts through mass media such as zero carbon or less microplastics in the sea, and this can be done without blurring people's understanding of the science and facts such as climate change.

As said above, there is no clear definition of environmental identity, and there is no terminology for the child's lived experience with nature. But I use a social work perspective and my experience of working with children to re-imagine the above as eco-ethnography. By the term eco-ethnography, I mean how children (and adults) construct their environmental identity from the past and current experiences of the built and natural environment, which is influenced by play, and the socio-cultural context in which the above experiences occur. For example, ecological stress is causing species extinction of plants and animals the child may never meet. The above lost flora and fauna will be an imaginary anthropomorphic friend about what could have been, what might have been, and possibly what should have been (abundance of species diversity). Given the above comment of extinction, loss, and uncertainty, I am mindful that exposure of harm caused by humans to the natural world may create a sense of helplessness and dysfunction such as eco-anxiety in children (and adults). I reflect, eco-ethnography is one approach for the child form as sense of environmental self within a bigger ecological picture while still being able to play and enjoy nature and be hopeful for the future.

Environmental identity and well-being

Linking with the above discussion about the positive effects of anthropomorphism, there are other benefits of well-being associated by making a connection with nature. For example, Mayer et al. (2009) discuss an environmental psychology approach across three areas which are: i) connection to nature is a potential mediator to well-being; ii) exposure to nature helps the individual to reflect complex socio-emotional life problems; and iii) the difference between real and virtual contact with nature on well-being. Although the above research was on adults, there is no reason the above concept should not apply to children and young people. To give context about a connection with nature, Petty (2002) suggests there are about 350,000 generations of human that have lived close to the land as hunter-gatherers, which gave our ancestors a pow-

erful sense of attachment and identity with the natural environment. Therefore, it seems likely being away from nature in a built environment may have some detrimental effects on well-being. Perhaps the concept of environmental identity and supporting children's well-being requires going back to our roots and making a reconnection with nature as part of the 'everydayness' of life.

Green (2016) suggests the natural world inspires a sense of curiosity and wonder in children, and a connection to the natural world; but it can also cause fear of the unknown. To develop the above, Green et al. (2016) propose an environmental identity development model as a theoretical framework consisting of three approaches that originate from Lucus (1979) and progressively develop a child's environmental identity. These are i) education *in* the environment, ii) education *about* the environment, and iii) education *for* the environment. Additionally, environmental identity is a two-way process of how nature shapes the child, and how external influences of family and socio-cultural practice shape the child's feelings, thoughts, and action towards the natural environment. For example, family attitudes about getting wet and muddy, stay in versus stay out, and geographic settings and accessibility of natural spaces. Green (2016) argues the more positive the experience, the more likely the child will go out and adventure, discover, imagine, and develop their environmental identity.

The three approaches suggested by Green et al. (2016) to the environmental identity development model are explored further. First, education *in* the environment is about a child's trust with nature for the child to feel comfortable, curious, and confident to venture outside in nature. Second, education *about* the environment means a child has an opportunity to claim place through play, and environmental competency, skills and knowledge that can be carried forwards to sustainable futures. Third, education *for* the environment includes learning about environmental concerns, which can help manage eco-anxiety. In reflection, I suggest actions to reduce harm to nature and help nature can replace a child's eco-anxiety with hope. There are compelling arguments about the benefits of nature-play, the use of forest school, which can be termed a type of sustainable well-being. Perhaps now is the time to reintroduce Education for Sustainable Development back into the school curriculum, and help children rediscover their environmental identity and sense of place.

Managing eco-anxiety

The child's well-being through connection with nature is explored by Mayer et al. (2009) who suggest spending 15 minutes in the natural environment or watching a virtual natural environment increased a person's connectedness to nature, triggered positive emotions, and attentional capacity to spend time reflecting on complex life problems. Additionally, individuals experienced a decrease in negative emotions such as aggression, anxiety, and depression. Time spent watching virtual images of nature had less effect on promoting well-being. I add, the ability to critically reflect is subject to age, stage, understanding, and personal agency such as self-influence and meaningful action. Mayer et al. (2009) add the mediator for environmental identity and well-being is still unclear, but the benefits are tangible.

But what happens when children watch the unfolding of natural world through the mass media coverage of forest fires, floods, melting ice caps, and protests about climate change? I use climate change as an umbrella term, but add that climate change means species extinction, loss of biodiversity, and stress on ecological boundaries. Hickman (2020) explains children and young people have been feeling frightened for a long time about climate change. Often the child's feelings are framed by adult narratives of avoidance, denial, fear, lies, and misunderstanding. So here is the deal in simple terms - climate change is big; it affects everyone, and every living thing, but we can do something about it. What scares children the most is adult failure to take urgent action to reverse climate change or at least try and protect the fragile eco-system that sustains life on the planet. Adults know what to do to help the planet recover which includes protecting nature, making smarter food choices (e.g., producing less meat), using alternatives to

mass agriculture, consuming less the resources of earth, and stepping back from consumerism. But does the current generation want to make sacrifices for future generations by living a simple, slower lifestyle, that is more in balance with nature. Hickman (2020) adds children are left out of discussions to heal the planet which is disturbing because children will inherit the mess earlier generations have caused. That does not mean adults should put heavy burdens on children to solve climate crises, but children do need a voice to imagine and build hopeful and sustainable futures as well as a narrative about how they want the world to be.

Eco-anxiety is a term used to describe the emotions and experiences of children about climate change. Hickman (2020) uses a social work perspective as powerful approaches to manage eco-anxiety. A few examples include 'managing it'. For example, there is no specific diagnosis for eco-anxiety; however, the term eco-anxiety supplies a framework to hold global concerns of many, and allows children to share worries and feel less alone. The second approach Hickman (2020) argues is 'feeling it' which is about recognising fear, terror, loss, and injustice, and that all associated feelings are accepted, heard, and understood. Young (2022) suggests eco-anxiety is an alert system to deal with a problem, something big, and something urgent. Young (2022) adds eco-anxiety has three outcomes of flight, fight, and freeze. I suggest another outcome of ambivalence such as being unsure of what to do or turn feelings into positive agency is a catalyst for change. Perhaps the most disturbing of Hickman's (2020) findings were the comments that children did not want to go outside or make an attachment to place because they felt guilty or sad about the wildlife that could be lost due to climate change. I think this is a worrying disconnect from the natural world and goes against the concept of environmental identity. Rather than pathologizing eco-anxiety, Hickman (2020) suggests eco-anxiety becomes a healing process that starts with validation of the child's anxiety and adults being honest about climate change. Taking small steps such as children joining a beach clean, rewilding a local area, and raising awareness of climate issues is enough meaningful action to make change, and if everybody all over the world does a little bit to protect the planet, we can make the world better, and we can make ourselves better by worrying less about the natural world.

The above discussion about a child's environmental identity has similarities with attachment theory (Ainsworth, 1978) and separation anxiety. There are four types of attachment: ambivalent attachment, avoidant attachment, disorganised attachment, and secure attachment. Ambivalent attachment is when the child cannot rely on their primary carer for comfort or reassurance. Avoidant attachment is when the child has no preference of carer. Disorganised attachment refers to a child resisting contact because the carer is inconsistent and unreliable. Lastly, a secure attachment is formed through a dependable, reliable, trusted and safe relationship between child and adult. I wonder if the same types of attachment can be applied between the child and nature about the proximity and longevity of reciprocal relationships. Therefore, if the world is fearful, unknown and poorly through climate change, does the lack of a secure attachment led to (separation) eco-anxiety. For example, if the child makes an emotional investment in nature (environmental identity) will the world be there for the child in the future. Can the reversal of climate change help Mother Earth to keep us safe and enable a secure attachment to place, and in doing so reduce eco-anxiety in children?

Lockdown - places and space to play

The Government Response to managing risk in the COVID-19 pandemic was to close all outdoor play areas from February 2021 (GOV.UK. 2021), along with adaptations to existing guidance about play areas to reduce the risk of transmission (hse.gov.uk. 2012). For example, cleaning play equipment after use, restricting the number of children who can use the play area at the same time, a one-way system for outdoor gyms, and keeping an obligatory two metre distance from other people. The above sounds great, but what about the risk to the child's welfare from not being able to play and be outside, and does the lack of outside play exasperate concerns about eco-anxiety? In critique, the above regulations (hse.gov.uk. 2012) try and promote a

balanced approach to play, suggesting play should expand the child's learning, and stretch their abilities. That said, many play areas are still closed. I reflect, the impact of lockdown on a child's environmental identity could have gone two ways, either lockdown restrictions caused children to have a disconnect from nature or lockdown restrictions made children yearn to be outside and discover more about the natural world.

In contrast to the above closure of play areas, and as a response to COVID-19 restrictions, the United Nation's ask all signatories of the UNCRC (United Nations Convention on the Rights of the Child) to get creative about upholding Article 31, adding alternative options must be supplied to meet the child's right to engage in play, and recreational activities (UNICEF, n.d.). Casey and McKendrick (2022) suggest three narratives of play in lockdown which are: i) play in crisis, ii) the threat to play in crisis, and iii) play as a remedy to crisis. The above narratives focus on general comments 17 (playscotland.org, 2013) that go with Article 31, and state play must be free from stress such as worries from Covid-19. For example, i) play in crisis has several aspects. Firstly, how to help the child manage worries about meeting friends, touching play equipment or sharing sweets and toys. Often the child's worries are exasperated by adult anxiety and aversion to risk. Secondly, outdoor play areas need to be accessible, open, and enable children freedom to play unaccompanied but within easy reach of a trusted adult. Thirdly, do play areas encourage children to access the natural environment and the animal world. Fourthly, play enables the child to claim place as a space for curiosity and imagination that shapes the child's environmental identity and well-being. Regarding ii) the threat to play in crisis, Casey and McKendrick (2022) add play is often compromised with a focus on formal education, and the added financial burden upon councils and community groups to upkeep play areas. Play is often seen as an arranged event as opposed to a spontaneous activity or the happenstance of meeting a friend at the park to play with. I suggest play is for fun, play is learning, and is play because you can. But restriction of play is also used by adults as punishment. I reflect, the denial of play adds to the stress experienced by some children in the pandemic and could led a gap in the child developing a sense of environmental identity. Lastly, point iii) play as a remedy to crisis, sees Casey and McKendrick (2022) argue children's developmental and well-being needs did not stop during the pandemic. Play is needed more than ever so that children can adapt and make sense of their environmental identity, and life experience such as global crises of the COVID-19 pandemic and climate change.

Summary

There is no definitive answer about what defines environmental identity, but the above discussion explored social construction and anthropomorphism as ways for children to connect with the natural world. The right to play, nature-assisted learning such as forest schools, education for sustainability, and being in a natural environment for 15 minutes can support sustainable well-being. Lockdown saw many play areas closes and remain closed, which may have caused a detachment from the natural world and a gap in the child's environmental identity. I argued this is a concern because children use their lived experiences of being in nature, knowing about nature, and play to shape their eco-ethnography. The proximity and longevity of reciprocal relationships with nature was explored, and eco-anxiety was reframed as eco-compassion and a trigger for action. Additionally, children need a voice and be part of a narrative about the future. Based on the above discussions, I propose a sense of environmental identity can help children be the best version of themselves in an everchanging complex world. The challenge is how to re-engage children, this climate generation, with the natural world through post Covid-19 recovery and beyond, and enable children an everydayness of being curious, and confident in nature.

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Biography

Sam spent 20 years as a social worker with children and noticed a gap in social practice about the impact of the natural environment on the child's welfare, leading to a disconnect by social workers from the people and places they support. Sam's research explores how social workers can help children to reconnect and become curious and confident about being outside with nature. Sam argues, a broad understanding of environmental and sustainability type concepts as a wider theory base in social work education would prepare social work students for holistic practice, and in times of change, complexity, and uncertainty.

References

- Ainsworth, M. D. S. (1978). The Bowlby-Ainsworth attachment theory. *Behavioral & Brain Sciences*, 1(3), 436–438. <https://doi-org.uoelibrary.idm.oclc.org/10.1017/S0140525X00075828>
- Balunde, A., Jovarauskaite, L., & Poskus, M. S. (2019). Exploring the Relationship Between Connectedness with Nature, Environmental Identity, and Environmental Self-Identity: A Systematic Review and Meta-Analysis. *SAGE OPEN*, 9(2). <https://doi-org.uoelibrary.idm.oclc.org/10.1177/2158244019841925>
- Blatt, E. (2013). Exploring environmental identity and behavioral change in an Environmental Science course. *Cultural Studies of Science Education*, 8(2), 467–488. <https://doi-org.uoelibrary.idm.oclc.org/10.1007/s11422-012-9459-2>
- Bronfenbrenner, U. (1979). *The Ecology of Human Development*. Harvard Press.
- Casey, T., & McKendrick, J. H. (2022). Playing through crisis: lessons from COVID-19 on play as a fundamental right of the child. *INTERNATIONAL JOURNAL OF HUMAN RIGHTS*. <https://doi-org.uoelibrary.idm.oclc.org/10.1080/13642987.2022.2057962>
- Clayton, S., & Opatow, S. (2003). *Identity and the Natural Environment. The Psychological Significance of Nature*. The MIT Press.
- Gebhard, U., Nevers, P., & Billmann-Mahecha, E. (2003). Moralizing trees: Anthropomorphism and identity in children's relationship to nature. In Clayton, S. & Opatow, S. (Eds.), *Identity and the Natural Environment. The Psychological Significance of Nature*. pp. 91-97. The MIT Press.
- Green, C. (2016). Monsters or Good Guys: The Mediating Role of Emotions in Transforming a Young Child's Encounter with Nature. *Canadian Journal of Environmental Education*, 21, 125–144.
- Green, C., Kalvaitis, D., & Worster, A. (2016). Recontextualizing psychosocial development in young children: a model of environmental identity development. *Environmental Education Research*, 22(7), 1025–1048. <https://doi-org.uoelibrary.idm.oclc.org/10.1080/13504622.2015.1072136>
- Greenpeace. (2015, June 16). *Beyond reduce, reuse, recycle: The 9 'R's of a sustainable life*. <https://www.greenpeace.org.au/blog/beyond-reduce-reuse-recycle/>
- GOV.UK. (2021, May 18). COVID-19: Guidance for managing playgrounds and outdoor gyms. <https://www.gov.uk/government/publications/covid-19-guidance-for-managing-playgrounds-and-outdoor-gyms/covid-19-guidance-for-managing-playgrounds-and-outdoor-gyms>
- hse.gov.uk. (2012, September). *CHILDREN'S PLAY AND LEISURE – PROMOTING A BALANCED APPROACH*. Health and Safety Executive. <https://www.hse.gov.uk/entertainment/childrens-play-july-2012.pdf>
- Hickman, C. (2020). We need to (find a way to) talk about ... Eco-anxiety. *Journal of Social Work Practice*, 34(4), 411–424. <https://doi-org.uoelibrary.idm.oclc.org/10.1080/02650533.2020.1844166>
- Lucus, A. M. (1979). *Environment and Environmental Education: Conceptual issues and curriculum implications*. Australia International Press and Publications.

- Mayer, F. S., Frantz, C. M., Bruehlman-Senecal, E., & Dolliver, K. (2009, January 1). Why Is Nature Beneficial? The Role of Connectedness to Nature. *ENVIRONMENT AND BEHAVIOR*, 41(5), 607–643.
- Petty, J. (2002). *Agri-culture: Reconnecting People, Land and Nature*. Earthscan.
- playscotland.org. (2013). *United Nations: Convention on the Rights of the Child General Comment 17*. <https://www.playscotland.org/resources/united-nations-convention-on-the-rights-of-the-child-general-comment-no-17/>
- Stapleton, S. R. (2015). Environmental Identity Development Through Social Interactions, Action, and Recognition. *Journal of Environmental Education*, 46(2), 94–113. <https://doi-org.uoelibrary.idm.oclc.org/10.1080/00958964.2014.1000813>
- Tam, K. P., Lee, S. L., & Chao, M. M. (2013, January 1). Saving Mr. Nature: Anthropomorphism enhances connectedness to and protectiveness toward nature. *JOURNAL OF EXPERIMENTAL SOCIAL PSYCHOLOGY*, 49(3), 514–521.
- UNICEF. (n.d.). *THE UNITED NATIONS CONVENTION ON THE RIGHTS OF THE CHILD*. <https://www.unicef.org.uk/wp-content/uploads/2016/08/unicef-convention-rights-child-uncrc.pdf>
- Young, K. (2022). *How to Talk to Children and Teens About Eco-Anxiety. The words that will turn anxiety into hope, courage, and direction*. Hey Sigmund. <https://www.heysigmund.com/how-to-talk-to-children-and-teens-about-eco-anxiety/>
- Waytz, A., Morewedge, C. K., Epley, N., Monteleone, G., Gao, J.-H., & Cacioppo, J. T. (2010, January 1). Making Sense by Making Sentient: Effectance Motivation Increases Anthropomorphism. *JOURNAL OF PERSONALITY AND SOCIAL PSYCHOLOGY*, 99(3), 410–435.

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RESEARCH ARTICLE

Effects of Attention and Congruence on Judging True and False COVID-19 News Headlines

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Abstract

Fake news has become increasingly prevalent in the United States, especially during the outbreak of the COVID-19 pandemic in the U.S. since March 2020. This has caused a significant number of Americans to believe that COVID-19 is a hoax rather than a real problem. Fake news spreads easily and quickly through social media, where people are often inundated with advertisements and thumbnails of false headlines along with pseudo-reliable media outlets. The purpose of the current study is to analyze how divided attention and the congruence of news headlines and news sources affect the identification of true and false news headlines about the COVID-19 pandemic. Participants ($N = 27$) saw 48 news headlines paired with 48 sources and judged the validity of the headline. In the congruent condition, true and false headlines were paired with reliable and unreliable sources, respectively. In the incongruent condition, these pairings were mixed up: true headlines were accompanied by unreliable sources, and false headlines reliable sources. In 24 out of 48 trials, participants also did mental math problems while evaluating the news (divided attention). The results showed that when dividing attention, participants performed better in trials either with congruently matched headlines and sources or with incongruent matchings of false headlines and reliable sources. There were also unexpected patterns of results, which are further discussed along with some methodological revisions for future research.

Keywords: attention, congruence, news media, social media, coronavirus

Every year, fake news, or fabricated stories and reports of events, is more and more prevalent in the United States. People suffer from many of its real-life consequences, some of which are lower trust in science, decreased empathy, greater inequality, and increasing polarization (Lewandowsky et al., 2017). These problems have greatly escalated with the outbreak of the COVID-19 pandemic in the U.S. since March 2020. Fake news has contributed to federal responses' failure to address the severity of the virus and provide necessary strategies to contain the spread. It has also prevented countless Americans from perceiving COVID-19 as a threat or even as a real problem, and rather as a conspiracy. Such negative outcomes and a consequent sense of urgency have motivated us to carry out this study.

Previous studies about fake news have made limited attempts to study the role of attention in the perception of fake news to date. Pennycook et al.'s (2018) examination of the influence of prior exposure to fake news on the perception of its accuracy is the most related analysis we can find. In this study, participants who previously saw false news headlines even once could accurately evaluate their validity both in the same session and seven days later. The researchers observed this "illusory truth effect" for fabricated headlines when they were not fully credible, verified, or consistent with participants' political ideologies. However, we argue that participants' prior exposure and attention to a false piece of news are not identical to each other. In the former case, people could see and skim over a news headline without much processing of it, which we can arguably still consider to be exposure to the news. Attention to a news headline, on the other hand, implies deeper processing of the content itself. Unfortunately, these two concepts are not different from each other in real life because most people do not spend a lot of time reading a news article or read the news they have shared on their social media profiles (Haile, 2014). Additionally, 59% of shared links on social media websites do not receive further clicks (Gabelkov et al., 2016), so people may form judgments of news articles based solely on what they can understand from a quick skim of the headlines.

We argue that a plausible reason for this scarcity of research on attention in misinformation processing is the recent development of the research topic at the time of our research. According to Lewandowsky et al. (2017), synonyms of fake news, such as "post-truth" and "post-fact," were unfamiliar terms in 2012. However, four years later, "post-truth" became Oxford Dictionaries' international word of the year, given the Brexit vote and Donald Trump's victory in the 2016 presidential election (Flood, 2016). Many studies have unanimously agreed that fake news spread quickly on social media, which allows easy, instantaneous content sharing. Vosoughi et al. (2018) reported that false news reached a greater number of Twitter users at a faster pace than real news, especially when the content was political.

Following many studies before us, we will give our participants a task that would involve them in making judgments about news headlines, which may depend on many factors like time pressure and previous knowledge and opinions about COVID-19. We looked at a similar study by Bago et al. (2020), which focus on measuring the different levels of effectiveness of using either intuition or deliberation when judging the validity of true and false headlines. They performed this with 1,635 participants who were given a series of headlines and asked to respond with their initial response under time pressure, after which they were asked to give a second answer with no time constraints (and allowing them to think more deeply). The findings revealed that participants believed more false headlines than true ones from their intuitive responses. They also found that deliberation leads to more corrections of previous nonrational (and false) beliefs, which suggests that deliberating before making a judgment will lead to a more accurate belief that relies less on biases.

Divided attention happens when cognitive resources are being used for more than one task at a given time. Previous research has consistently shown the detrimental effects of dividing attention over multiple activities, also known as multitasking, on memory (Firth et al., 2019; Middlebrooks et al., 2017). Participants in the study could still recall the most valuable words,

determined by a 10-point scale, while they were doing a digit-detection task, listening to music, or doing nothing else. However, Middlebrooks et al. (2017) reported that those assigned to the digit-detection task in the first group recalled fewer words than their counterparts in the other two groups. In a classroom setting, dividing attention over laptops, tablets, or cell phones and the ongoing lecture could impair students' ability to retain memory of the lecture in the long term, thus negatively impacting their exam scores, yet leaving their comprehension of the lecture intact (Gaspelin et al., 2013). These researchers also demonstrated that divided attention, which caused greater difficulty during the learning process, failed to enhance memory retention for the learned materials.

We argue that divided attention, two proxies of which are error rates and reaction time, is important for further investigation in this misinformation literature because it could interact with an individual's ability to make judgments about news in an ideal environment. In our study, error rates and reaction time reflect the extent to which participants' judgments are enhanced or impaired as a function of cognitive resources. Using basic programs and protocols, we aim to simulate the nature of reading and processing news in the social media environment in the current study by setting a pre-determined limit on the amount of time our participants can see and judge news headlines. This manipulation may not come close to participants' actual experience on Facebook or Twitter, but we expect participants to divide their attention or multitask to meet the demands of the experimental protocols.

In the current study, we also decided to examine the congruence and incongruence between news sources and news headlines because we thought individuals could use their perceived credibility of news media outlets as a possible heuristic to determine the validity of news. Sundar et al. (2007) explored the role of this heuristic, along with how long the story had been published and how many articles about the same story had come out of other news organizations, in people's perceived credibility of the message, perceived newsworthiness, and likelihood of clicking on the article. Given a news source with low perceived credibility, people were more likely to trust the message of the article if the article came out sooner and there were more outlets publishing related articles (Sundar et al., 2007). Furthermore, source credibility would not have as much effect on people's perceived credibility of the news if there had already been a lot of articles about that news. Also, Sterrett et al. (2018) could not find any effects of the perceived credibility of a news source on people's trust in an article nor any interaction between this factor and trust in the sharer of an article on people's trust in that article itself. However, what some people may identify as a credible news source may differ from others, which depends on their own biases and previous knowledge (Edgerly & Vraga, 2019). These mixed findings motivate us to investigate the potential interaction between the veracity of news headlines and the perceived credibility of news sources.

The Current Study

The purpose of the current study was to examine the effects of divided attention via multitasking and of congruence between headlines and sources on people's judgments of the veracity of COVID-19 news headlines. We paired true headlines with incongruent (or unreliable) news sources and vice versa so that we could see if participants would make more or fewer errors if they depended on the news sources to make their judgments. We were interested in the contributors to our ability to distinguish between real and false news headlines. We predicted that our participants, when dividing their attention over the main task and a mental arithmetic task, would make more errors in their identification of true or false news headlines, spend more time evaluating the validity of the news, and experience more interference from news sources incongruent with the validity of the news headlines. If substantiated, these hypotheses could inform journalists and social media companies about potential fake news to warn their readers and users, respectively, based on how they look. They may also equip people in the general public with knowledge about deception techniques to protect themselves from widespread false

information on social media.

Method

Participants

We began recruiting our participants during the last week of September 2020 by sending invitations to students enrolled in two psychology courses at Grinnell College at that time. In addition, we recruited other student participants at the college by publishing Facebook posts in the student groups and sending out emails or texts. We also used snowball sampling by connecting our family members and friends because we had only one week to collect the data. Therefore, we did not have enough time or resources to conduct a power analysis and recruit a correspondingly large sample. We did not collect and thus could not report any demographic information from our participants, but we limited our sample to people who were 18 years old and above and had spent most of their lives in the US, where news about the pandemic was still prevalent at the time of the study. All participants ($N = 27$) were also familiar with different common news sources and the concept of “fake news.” The Grinnell College Institutional Review Board (IRB) approved all procedures in the current study on the condition that participants provided their informed consent for their participation and received a debriefing about the actual purpose of the experiment after their completion.

Materials

The task programs we created consisted of 48 news headlines (see Table 1) and 24 difficult math problems (see Table 2). We gathered 30 of these news headlines from a recent study by Pennycook et al. (2020), which used articles published between February and March 2020. We compiled the remaining 18 news headlines from an online search for articles published between September and October 2020, using search terms such as “fake news,” “coronavirus,” and “COVID-19.” There were two types of news: real and fake, so our sample of news headlines included 24 true and 24 false headlines. We evaluated the validity of the news headlines we used in this experiment with FactCheck.org and Snopes.com and by consulting each other. The 24 math problems consisted of four-operation math questions at the 4th difficulty level, which was obtained from the Maths Question Generator of MathsBot.com.

To accommodate participants whose computers used different operating systems, we used two separate programs to design the task. People who had access to a Windows computer carried out the task using the E-Prime 3.0 software (Psychology Software Tools, Pittsburgh, PA). This version included a response time tracker and a randomization process regarding the order and matching of news sources and news headlines. Windows users received a link to download this version as a .exe file, which automatically started running after they opened the file. People with computers running other operating systems (e.g., macOS) received a Microsoft PowerPoint (Microsoft 365 2020, Version 16.42) file of the task. To account for all four possible combinations of the two variables of interest (i.e., attention and headline-source congruency), we prepared four versions of the Microsoft PowerPoint file. For two versions, participants first saw 12 congruent and 12 incongruent pairs of news headlines and sources, each of which was accompanied by a math problem, and then saw only 12 congruent and 12 incongruent pairs of news headlines and sources. For the other two versions, participants first saw only 12 congruent and 12 incongruent pairs of news headlines and sources, followed by 12 congruent and 12 incongruent pairs of news headlines and sources, each of which was accompanied by a math problem. These four versions used a preset process and did not include a response time tracker. macOS users received a link to download the answer sheet and one of these four versions as a .ppsx file, which automatically started running after they opened it. Despite certain differences, both E-Prime Go and Microsoft PowerPoint versions consisted of the 48 news headlines with 24 alternating math problems and the pairings of reliable and unreliable news sources with true and false news headlines. Our full

materials are available on OSF (osf.io/spuw3).

Procedure

Participants were randomly assigned to 4 different groups to control for order effects. We divided these groups by attention and congruence of news sources. For attention, two groups divided their attention first, working on 24 alternating math problems through the first half of the task. The others divided their attention later through the second half of the task. For example, in both the E-Prime Go task and PowerPoint task, a participant in the former two groups assigned to the divided attention condition in the first half received one difficult math problem to solve within 30 seconds. After working out the solution, they saw a real or fake news headline (e.g., “Iran now has the highest coronavirus death toll outside of China, threatening the wider Middle East” or “Vitamin C Protects Against Coronavirus,” respectively) paired with a source (e.g., “MICRO-TRACEMINERALS.COM”). The participant then had ten seconds to decide whether what they read was true or false. We imposed this time limit to prevent the participant from using search engines to find the tested headlines and check their answers. If they made their judgment before the time was over, they could move on to the next stimuli, which were another 23 sequences of math problems and news headlines. After completing the news judgment task whilst solving math problems, they only saw and provided their judgments on 24 news headlines paired with their sources. Overall, participants in every group saw 12 true and 12 false news headline trials, each of which was followed by math problems, and another 12 true and 12 false trials of news headlines only. We used this same method to include the congruence of news sources as a variable so that there were no repeating news sources.

After providing informed consent, participants received an email from us with specific instructions for their assigned groups. After completing either the E-Prime Go task or the PowerPoint task, participants submitted their data through an electronic survey, an email, or the E-Prime Go server. All the participants then received a debriefing form via email after we confirmed their completion of the task. One week later, we invited three participants to introspect about their thoughts at the time of the experiment through five questions (see Appendix). These informal interviews served to provide us with some possible explanations for our results.

Statistical Analysis

In general, we tested our hypotheses by conducting a 2 (news headline: real, fake) x 2 (attention: full, divided) x 2 (news source: congruent, incongruent) analysis of variance (ANOVA) with repeated measures to examine the number of accurate judgments about the validity of the news headlines presented under different conditions as well as the time participants spent on the task in different conditions. Despite a small, underpowered sample that did not warrant a normal distribution and could have violated the assumptions, we chose ANOVA as the main statistical test because we had two categorical independent variables and two dependent variables treated as continuous. Both our knowledge of statistics at the time and time constraints on running this study prevented us from exploring other more appropriate techniques to analyze this small dataset. We conducted all these analyses in SPSS 20. We set the alpha level for all following statistical analyses to be .05. We did not correct our results for multiple comparisons so we could find significant results, even though this practice increased the false positive results given our small sample size.

Results

Accuracy

We observed that on average, our participants correctly identified the truthfulness of approximately 4 ($M = 4.03$, $SE = 0.12$) in a block of 6 headlines. However, there was no significant

main effect of news headline, $F < 1$, $p = .467$, and no significant interaction between it and attention, $F(1, 26) = 1.24$, $p = .276$. Instead, we found a significant main effect of not only attention, $F(1, 26) = 20.49$, $p < .001$, $\eta_p^2 = .44$, but also news source, $F(1, 26) = 6.88$, $p = .014$, $\eta_p^2 = .21$. Dividing attention to two tasks ($M = 4.33$, $SE = 0.15$) surprisingly produced more correct identifications of news headline types than attending fully to the news headline evaluation task ($M = 3.73$, $SE = 0.12$). Greater accuracy was also observable for congruent pairings of headlines and sources ($M = 4.25$, $SE = 0.13$) than for incongruent ones ($M = 3.82$, $SE = 0.16$). The analysis also revealed significant two-way interactions between news headline and news source, $F(1, 26) = 5.93$, $p = .022$, $\eta_p^2 = .19$ (see Figure 1), and between news source and attention, $F(1, 26) = 9.95$, $p = .004$, $\eta_p^2 = .28$ (see Figure 2). The three factors surprisingly showed a significant three-way interaction as well, $F(1, 26) = 12.38$, $p = .002$, $\eta_p^2 = .32$ (see Figure 3).

Response Time

Because we carried out the experiment virtually, we could not provide access to Windows computers to our participants. As a result, few of them ($n = 9$) could use E-Prime Go to submit data including their response time to us. A typical participant in our sample spent around 5 seconds evaluating the news headlines ($M = 4.861$, $SE = .212$). The analysis presented no significant main effect of or interaction between the three factors.

Order Effects

It was also important for us to check for order effects due to the within-subjects design of our experiment. In other words, we required some participants to look at a long series of news headlines with alternating math problems early in the experiment, while others experienced the interruption with math later. Therefore, practice effects and fatigue effects, for example, were potential threats to our results. We decided to run the aforementioned ANOVA test with an additional, between-subjects variable – order (math first, math later) – to examine whether accuracy rates varied across the two groups. The main effect for order was not significant, $F(1, 25) < 1$, $p = .615$, so the order at which math problems interfered with news headline evaluation trials did not matter in our experiment.

Discussion

We hypothesized that when people divided their attention by making judgments about news headlines and doing mental math problems simultaneously, they would spend more time on the judgment and make more errors during the judgment-making process. We suspected divided attention would deplete more cognitive resources than full attention, leading to participants' slower reaction time and greater errors in their validity judgments. However, we could not find support for either of the hypotheses. There was no statistically significant difference in participants' response time between the two conditions of news headline, attention, or news source. The rate of accuracy did not vary significantly between the participants who divided their attention at the beginning or those who divided at the end. However, they made more correct judgments when completing the tasks simultaneously (dividing their attention) than when they focused on only a series of news headlines (with full attention). We obtained partial support for our hypothesis about greater interference from incongruent headline-source pairs with multitaskers' performances than from their congruent counterparts. Specifically, dividing attention facilitated greater accuracy when news headlines were paired with congruent sources far more than when participants had full attention. When people saw headlines appear with incongruent sources, dividing attention was also more beneficial, but the difference was not as significant.

Limitations

It is important to note that there was a phenomenon beyond our prediction that emerged in this study. Participants' news judgments suffered significantly when they saw false news head-

lines paired with reliable news sources while pairing true headlines with unreliable sources saw a slight improvement in performance. We recorded this finding only when participants could pay full attention to the main task or were not tasked with mental math questions. Conversely, when participants had to take on two tasks, incongruently matched sources generated more errors than congruent pairings.

These unexpected events indicate to us that participants did not consider sources while examining the headlines. Previous studies on false memory and misinformation also found people's failure to monitor the source of misleading information (Belli et al., 1994; Lindsay, 1990) and the occasional insignificance of sources in judging truth (Brashier & Marsh, 2020). Emphasizing sources of news articles on social media platforms may also backfire (Dias et al., 2020). However, we have ruled out this explanation because it presents conflicting evidence concerning participants' responses to pairs of false headlines and reliable sources. In other words, we observe that participants took the reliable source into account when judging an unknowingly false headline. This approach suited them – the cognitive misers – because it prompted them to fall back on the sources they perceived as reliable (for making a decision) when given a headline they felt uncertain about. If participants did not adopt this approach during their judgment-making process, their confusion or uncertainty under the time pressure could use up more cognitive resources quickly. In this regard, another possible interpretation of the observations above is that a news source carries more authority when its accompanying headline is false than when it is true. This interpretation also appeared out of our post-hoc interviews with three participants to understand their thought processes during the experiment. Some of these participants shared that they included the supplemental news sources in their problem space only when they felt uncertain about the validity of the false news headlines. In other words, if they had a low level of confidence in their initial judgment, they were more likely to fall back on their knowledge of the news source as a last resort.

A third account of the unexpected findings comes from congruence between the source and the reader's political ideology. Edgerly and Vraga (2019) listed the ambiguity of a Twitter news account and the congruence between it and participants' political affiliations as determinants of participants' trust in that account. Additionally, the researchers suggested that the verification marks commonly seen alongside some Twitter accounts did not matter in credibility assessment as much as people thought, suggesting a need for Twitter to make those marks more salient or communicate more information to its users. Oyedeji (2010) also found this congruence important in how people perceived the credibility of news media outlets and their messages. By examining participants' perceptions of CNN and Fox News Channel, the author found support for the "credible brand model," which postulated that perceived customer-based brand equity and perceived congruence between the worldview of a person and that of the news media outlet determine the person's trust for the media outlet and its stories. In the current study, we did not check for this congruence between news sources and the participants' political views because of two reasons. First, time constraints on material preparation had prevented us from investigating individual differences in preference for certain political parties through exploratory analyses, which were performed by past studies (Edgerly & Vraga, 2019; Oyedeji, 2010; Pennycook et al., 2020). Besides, our study focuses only on the cognitive processes involved in carrying out the news headline evaluation task. However, we believe that these social factors, which contribute to the perception of credibility for the news, are important for us to keep in mind regarding the relevant content of our study (Osmondson et al., 2021). Therefore, future studies on fake news should ensure a careful examination of such differences in people's social identities to explain their results more fully (for a review, see Pennycook & Rand, 2021).

Another likely limitation of our study is the inconsistency in our selection of news sources. According to one interviewed participant, some headlines could have allowed people to judge their validity more easily than others because the former had a nonstandard or special phrasing

that is characteristic of fake news (e.g., multiple exclamation marks and irregular capitalizations). This problem could stem from our not laying down strict criteria for the content and the source of news in advance. Consequently, it could lead to better detection of false content in the news when people are doing multiple tasks at the same time and become cognitively busy. In such circumstances, superficial processing of the news is more likely than semantic processing because the former requires less mental effort than the latter. For superficially processed headlines, their inconsistency in formatting might be quickly recognizable, serving as one of many mental representations of fake news. Once this representation gets activated, it also prompts the activation of the concept of fake news or falsehood. Nevertheless, this is not what we have observed. Detecting false news headlines was less successful when participants had to solve math problems than when they performed only the main task. This result indicates that our manipulation, though incomprehensive, did not have serious effects on the experiment. Having said that, other researchers should seek to control not only what all the collected headlines convey but also how they look to a typical reader, which assumes collecting people's demographic information. Pennycook et al. (2021) raised valid concerns about designing headlines that sounded as equally partisan to a pro-Democrat as to a pro-Republican. In this regard, by completing a pre-test for the selected headlines and gathering data about participants' political affiliation, truth ratings of the headlines, familiarity with them, perceived partisanship of them, and the like (see Table 1 in Pennycook et al., 2021), researchers can ensure the content of the headlines would not interfere with its partisanship and cause some unexpected findings. Furthermore, the guidelines by Pennycook et al. (2021) provide a good model on which other misinformation researchers can rely.

Additionally, we did not create identical experimental conditions for all participants because we presented them with either the E-Prime Go version of the task or the PowerPoint one. We could not fully replicate the randomization of the stimuli (i.e., news headlines and math problems) inherent in E-Prime Go in the PowerPoint version. More specifically, while true and false news headlines in each of the four conditions (whether the participants divided their attention first or later and whether they saw congruent or incongruent headline-source pairs first or later) appeared in a random order in the E-Prime Go version, we had decided in advance the order of these true and false news headlines to make the PowerPoint slides correspondingly. Although we had made sure these differences were minimal and assumed they did not heavily affect the participants' experience, we understand this practice is vulnerable to unidentified confounds and recommend future researchers with limited resources and time against it. An obvious pitfall was our failure to control for when participants who used the PowerPoint version accidentally quit the program and did a quick online search for the news headlines without our knowledge. We did not have any built-in tools to record the number of mouse clicks or times participants closed the application. Although we found comparable performance among people who completed the experiment using two versions in the current study, we strongly suggest using survey software which provides everyone with access to the materials and allows researchers to manipulate the random assignment of participants, random presentation of the materials, and collection of behavioral data (e.g., response time and mouse clicks). A noteworthy example in misinformation studies after ours is Qualtrics.

Last but not least, our approach to participant recruitment was not methodologically sound, given the timing and setting of this study. We had less than a month to collect our data from a small number of college students from a small U.S. liberal arts college with a student population of under 2,000. These individuals had plenty of experience with critical thinking and had to regularly provide critiques on what they read from their various courses and assignments. Given this academic background, student participants in this sample presumably read and judged news headlines, especially false ones, better than or at least differently from the general population did. Besides, we gathered students enrolled in two psychology courses at that time, so they could know more about experimental design and cognitive psychology than an average person. These students – along with their parents and friends – were possibly aware of or able to guess

the purpose behind the math problems, which were to deplete their cognitive resources, and thus tried harder to do the task.

At the same time, our snowballing recruitment method also greatly contributed to the low representativeness of the sample. Although we tried to keep the participants blind to our original hypotheses and experimental conditions, we did not conduct any manipulation checks to explicitly test for their awareness of our research question. These individual differences in their performance could have interfered with our manipulation and, along with the small sample size, prevented us from validating and generalizing the results to a broader population. We suspect we violated many assumptions in our statistical analyses, given a small N , which increased the risk of a false rejection of our null hypotheses (Type I error). Specifically, we had a sample of only 27 people for eight pair-wise comparisons, which did not warrant high statistical power. We recommend conducting power analysis and sensitivity analysis in advance to arrive at a more methodologically sound sample size that warrants the assumptions of statistical tests. Researchers should also study the literature in advance to arrive at a better estimate of the group differences in truth ratings of false and true news headlines and to decide on an appropriate data analysis protocol instead of doing ANOVA more exploratorily.

Implications

Despite lacking statistical power to make reliable inferences, results from the current study inform us about the potential different effects of real and fake news on our judgments in different situations. The general public can greatly benefit from education on deception techniques like the approach taken by the current study to avoid falling for fake news on social media. Awareness of distractors in the online environment may help individuals stay more alert to false content, and taking a pause to check potentially misleading information surely helps not only the reader but also the community around them, such as their family and friends. At the same time, journalists, newspaper editors, and social media companies should be aware of how these tactics affect their audience and make a concerted effort to truthfully communicate to their readers and users as well as effectively warn people about these tactics.

Conclusion

Our study is among the first to examine the roles of attention, specifically divided attention, and the congruence of news headlines and news sources in the identification of true and false news about the COVID-19 pandemic. We have extended this line of research about fake news to include attention and perceived similarity between the content and source of news. Certain patterns in the results show a trend that when participants divided their attention over tasks, they correctly judged congruent matchings of headlines and sources, regardless of true or false news headlines, and incongruent matchings of false headlines and reliable sources. These findings turn out to be more complex than we have anticipated, and our possible explanations vary between individuals given our informal post-hoc interviews. It follows that individual differences play an important role when it comes to making judgments about the validity of news headlines. Therefore, understanding how individuals use their problem space when evaluating important news may be helpful to explore in future studies.

Conflict Of Interest

We have no known conflict of interest to disclose.

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help us grow our sample size.

Biography

Phuc Huynh Le is a first-year cognitive psychology graduate student working in Dr. Nadia Brashier's lab at Purdue University. He previously graduated from Grinnell College in May 2022 with a psychology major and two concentrations in neuroscience and statistics. His current research interests involve the cognitive and social determiners of how misinformation beliefs are formed and maintained. Phuc is also interested in social media interventions to protect people from falling for online misinformation.

Josephine Blumenthal is a 4th year studio art major at Grinnell College. With a wide range of interests, Josie explores the complexity of everyday life by dilating between narrow and broader experiences of sensation and perception through the interaction of colors, shapes, and spontaneous movement. Although she enjoys quiet time, Josie loves to sing, dance, and play tennis with her friends during her free time.

References

- Bago, B., Rand, D. G., & Pennycook, G. (2020). Fake news, fast and slow: Deliberation reduces belief in false (but not true) news headlines. *Journal of Experimental Psychology: General*, *149*(8), 1608–1613. <https://doi.org/10.1037/xge0000729>
- Belli, R. F., Lindsay, D. S., Gales, M. S., & McCarthy, T. T. (1994). Memory impairment and source misattribution in postevent misinformation experiments with short retention intervals. *Memory & Cognition*, *22*(1), 40–54. <https://doi.org/10.3758/bf03202760>
- Brashier, N. M., & Marsh, E. J. (2020). Judging truth. *Annual Review of Psychology*, *71*, 499–515. <https://doi.org/10.1146/annurev-psych-010419-050807>
- Dias, N., Pennycook, G., & Rand, D. G. (2020). Emphasizing publishers does not effectively reduce susceptibility to misinformation on social media. *Harvard Kennedy School (HKS) Misinformation Review*. <https://doi.org/10.37016/mr-2020-001>
- Edgerly, S., & Vraga, E. K. (2019). The blue check of credibility: Does account verification matter when evaluating news on twitter? *Cyberpsychology, Behavior, and Social Networking*, *22*(4), 283–287. <http://doi.org/10.1089/cyber.2018.0475>
- Firth, J., Torous, J., Stubbs, B., Firth, J. A., Steiner, G. Z., Smith, L., Alvarez-Jimenez, M., Gleeson, J., Vancampfort, D., Armitage, C. J., & Sarris, J. (2019). The “online brain”: How the Internet may be changing our cognition. *World Psychiatry*, *18*(2), 119–129. <https://doi.org/10.1002/wps.20617>
- Flood, A. (2016, November 15). ‘Post-truth’ named word of the year by Oxford Dictionaries. *The Guardian*. Retrieved from <https://www.theguardian.com/books/2016/nov/15/post-truth-named-word-of-the-year-by-oxford-dictionaries>
- Gabielkov, M., Ramachandran, A., Chaintreau, A., & Legout, A. (2016). Social clicks: What and who gets read on Twitter?. *SIGMETRICS '16: Proceedings of the 2016 ACM SIGMETRICS International Conference on Measurement and Modeling of Computer Science*, 179–192. <http://dx.doi.org/10.1145/2896377.2901462>
- Gaspelin, N., Ruthruff, E. & Pashler, H. (2013). Divided attention: An undesirable difficulty in memory retention. *Memory & Cognition*, *41*, 978–988. <https://doi.org/10.3758/s13421-013-0326-5>
- Haile, T. (2014, March 9). What you think you know about the web is wrong. *Time*. <https://time.com/12933/what-you-think-you-know-about-the-web-is-wrong/>
- Lewandowsky, S., Ecker, U. K. H., & Cook, J. (2017). Beyond misinformation: Understanding and coping with the “post-truth” era. *Journal of Applied Research in Memory and Cognition*, *6*(4), 353–369. <https://doi.org/10.1016/j.jarmac.2017.07.008>

- Lindsay, D. S. (1990). Misleading suggestions can impair eyewitnesses' ability to remember event details. *Journal of Experimental Psychology: Learning, Memory, and Cognition*, 16(6), 1077–1083. <https://doi.org/10.1037/0278-7393.16.6.1077>
- Middlebrooks, C. D., Kerr, T., & Castel, A. D. (2017). Selectively distracted: Divided attention and memory for important information. *Psychological Science*, 28(8), 1103–1115. <https://doi.org/10.1177/0956797617702502>
- Osmundsen, M., Bor, A., Vahlstrup, P., Bechmann, A., & Petersen, M. (2021). Partisan polarization is the primary psychological motivation behind political fake news sharing on Twitter. *American Political Science Review*, 115(3), 999–1015. <https://doi.org/10.1017/S0003055421000290>
- Oyedeji, T. A. (2010). The credible brand model: The effects of ideological congruency and customer-based brand equity on news credibility. *American Behavioral Scientist*, 54(2), 83–99. <http://doi.org/10.1177/0002764210376312>
- Pennycook, G., Binnendyk, J., Newton, C., & Rand, D. G. (2021). A practical guide to doing behavioral research on fake news and misinformation. *Collabra: Psychology*, 7(1): Article 25293. <https://doi.org/10.1525/collabra.25293>
- Pennycook, G., Cannon, T. D., & Rand, D. G. (2018). Prior exposure increases perceived accuracy of fake news. *Journal of Experimental Psychology: General*, 147(12), 1865–1880. <http://doi.org/10.1037/xge0000465>
- Pennycook, G., McPhetres, J., Zhang, Y., Lu, J. G., & Rand, D. G. (2020). Fighting COVID-19 misinformation on social media: Experimental evidence for a scalable accuracy-nudge intervention. *Psychological Science*, 31(7), 770–780. <http://doi.org/10.1177/0956797620939054>
- Pennycook, G., & Rand, D. G. (2021). The psychology of fake news. *Trends in Cognitive Sciences*, 25(5), 388–402. <https://doi.org/10.1016/j.tics.2021.02.007>
- Sterrett, D., Malato, D., Benz, J., Kantor, L., Tompson, T., Rosenstiel, T., Sonderman, J., Loker, K., & Swanson, E. (2018). Who shared it?: How Americans decide what news to trust on social media. *NORC Working Paper*, WP-2018-001. Chicago: NORC.
- Sundar, S. S., Knobloch-Westerwick, S., & Hastall, M. R. (2007). News cues: Information scent and cognitive heuristics. *Journal of the American Society for Information Science and Technology*, 58(3), 366–378. <https://doi.org/10.1002/asi.20511>

Table 1*List of News Sources and Their Corresponding Media Outlets*

Source	News Headline	News Media Outlet	Type
O	Spread of coronavirus in U.S. appears inevitable, health officials warn, as Trump defends response	WASHINGTONPOST.COM	T
O	Trump spent the past 2 years slashing the government agencies responsible for handling the coronavirus outbreak	BUSINESSINSIDER.COM	T
O	Coronavirus Infections Increase in Italy	WSJ.COM	T
O	Why airport screening won't stop the spread of coronavirus	SCIENCEMAG.ORG	T
O	Europe's Coronavirus Outbreak Worsens, With Italy at Forefront	NYTIMES.COM	T
O	Coronavirus: 'Many People' In U.S. Will Be Exposed To Virus At Some Point, CDC Says	NPR.ORG	T
O	Coronavirus spread could last into next year, but impact could be blunted, CDC official says	STATNEWS.COM	T
O	Coronavirus: Israel to bring in 14-day quarantine for all arrivals	BBC.COM	T
O	Coronavirus poses tough challenge for economic policymakers	APNEWS.COM	T
O	Scientists warn nCoV more infectious than SARS, but experts have doubts	CIDRAP.UMN.EDU	T
O	Coronavirus: We need to start preparing for the next viral outbreak now	THECONVERSATION.COM	T
O	Amazon plans to prosecute sellers for price gouging during coronavirus outbreak	CNET.COM	T
O	\$425M in World Bank catastrophe bonds set to default if coronavirus declared a pandemic by June	WASHINGTONEXAMINER.COM	F
O	Is Colloidal silver a cure for coronavirus?	FILMDAILY.CO	F
O	Coronavirus: North Korea's First Confirmed Patient Shot Dead	NAIJALIVETV.COM	F
O	Coconut Oil's History in Destroying Viruses, Including Coronaviruses	HEALTHIMPACTNEWS.COM	F
O	Governor Cuomo Signs Law Using Coronavirus as an Excuse to Take 'Temporary' Dictatorial Powers	BLUNTFORCETRUTH.COM	F
O	With Coronavirus Concerns Heightened, 328 Chinese Nationals Caught at Southern Border Trying to Enter U.S. Illegally	TEXASINSIDER.ORG	F

Source	News Headline	News Media Outlet	Type
O	Vatican confirms Pope Francis and two aides test positive for Coronavirus	CBN2.COM	F
O	Florida hospital reports a coronavirus 'infestation' with multiple confirmed patients	NEWSBREAK.COM	F
O	Coronavirus in China: 23 Million QUARANTINED, 2.8 Million Infected; 112,000 DEAD	HALTURNERRADIO-SHOW.COM	F
O	Vitamin C Protects Against Coronavirus	MICROTRACEMINERALS.COM	F
O	University of Tennessee scientists may have found coronavirus cure	FOX46.COM	F
O	Unbelievable — Gates Foundation Predicted 65 Million Deaths Via Coronavirus 3 Months Ago!!!	COERCIONCODE.COM	F
O	Amid coronavirus outbreak, Carnival Cruise Line offers on-ship credits to passengers who don't reschedule	FOXNEWS.COM	T
O	Iran now has the highest coronavirus death toll outside of China, threatening the wider Middle East	CNBC.COM	T
O	Police Departments Are Spreading Coronavirus Misinformation As A Joke	BUZZFEEDNEWS.COM	T
N	Corona-sniffing dogs start work at Helsinki Airport	YLE.FI	T
N	Coronavirus latest: Florida paves way for full capacity in restaurants and bars	FT.COM	T
N	Science academies sound alarm on political interference	POLITICO.COM	T
N	With Daily Infections Hitting a Record-High, Critics Say the U.K. Hasn't Learned From Its Mistakes	TIME.COM	T
N	Odds of coronavirus infection greatly increase with poverty, CDC says	NEWS.YAHOO.COM	T
N	Covid Antibodies Endure Over Six Months in China Trial Subjects	BLOOMBERG.COM	T
N	US health officials quietly modify COVID testing guidelines, sparking a wave of confusion and bewildering experts	CHICAGOTRIBUNE.COM	T
N	Recent rise in COVID-19 cases threatens to slow L.A. reopening, mayor says	LATIMES.COM	T
N	Black Americans, suffering disproportionately from COVID-19, face a mounting mental health crisis	BOSTONGLOBE.COM	T
O	FEMA Proposes Martial Law to Contain Coronavirus	BEFOREITSNEWS.COM	F

Source	News Headline	News Media Outlet	Type
O	COVID-19 is Now Mutating Into Something Indescribable That is Now Found in Brazil!	TECHTIMES.COM	F
O	Experts think bats are the source of the Wuhan coronavirus. At least 4 pandemics have originated in these animals.	BUSINESSINSIDER.COM	F
N	American scientists say they've found potential COVID-19 cure	CANOE.COM	F
N	China's Massive Amount of Immunotoxic 5G Networking and the Wuhan Coronavirus: The Emperor's New Virus	FREEPRESS.ORG	F
N	Study finds hydroxychloroquine helped coronavirus patients survive better	MSN.COM	F
N	New Jersey COVID Numbers Remain Low, Governor Reports	TAPINTO.NET	F
N	Vitamin D Levels Impact COVID-19 Mortality Rates	HOMECEUCONNECTION.COM	F
N	CDC Says COVID Vaccine May be Distributed in Nov.	WEBMD.COM	F
N	Coronavirus: Combination of antimalarial medication and antibiotics could shorten COVID-19, researchers say	ORTHOSPINENEWS.COM	F
N	By the numbers, it's hard to see how lockdowns saved many lives	NYPOST.COM	F
N	New COVID-19 Mutation Is Thought To Be So Contagious That It May Bypass Social Distancing And Mask-Wearing Efforts	BROBIBLE.COM	F

Note. O represents news headlines and their corresponding sources that were from Pennycook et al.'s (2020) materials. N represents news headlines and their corresponding sources that were gathered by two authors of the current study. T represents true news headlines. F represents false news headlines. News headlines appear in the same order here as in the condition when participants started with divided attention to mental arithmetic tasks and news headline evaluation ones.

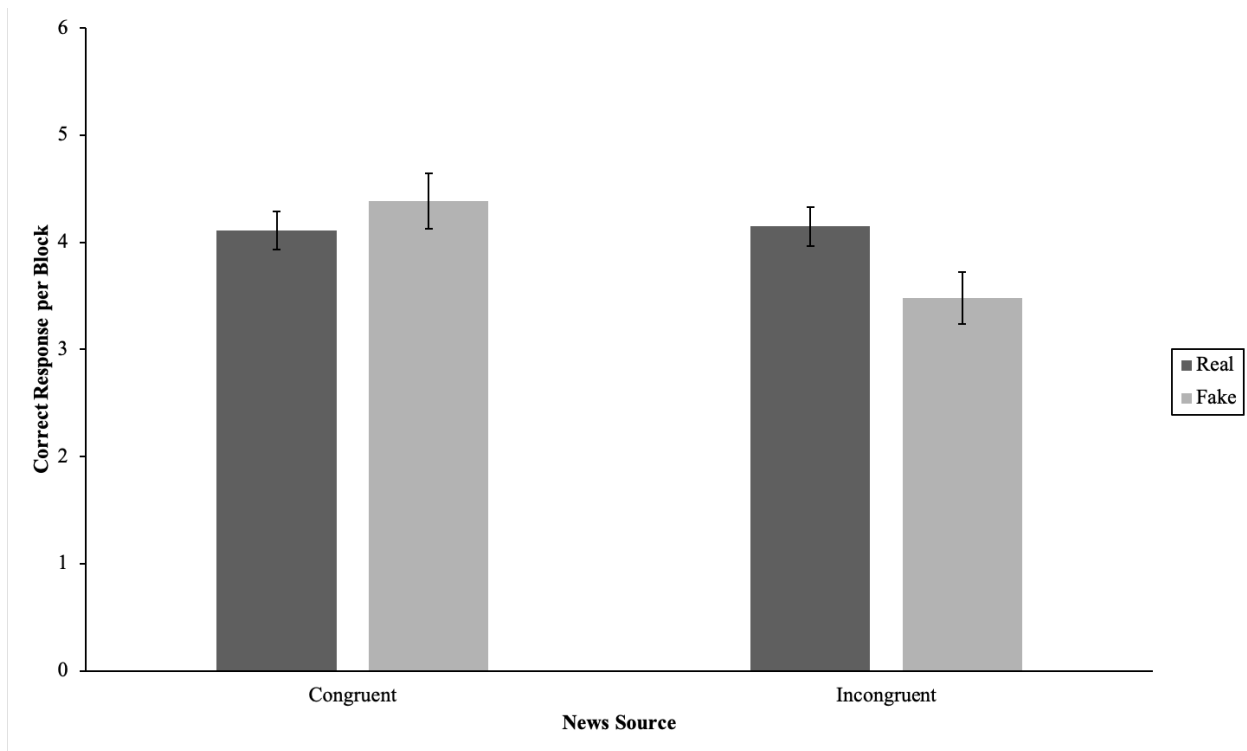
Table 2*List of Math Problems and Their Corresponding Answers*

Math Problem	Answer
$2064 \div 3$	688
37×75	2775
$615 - 277$	338
$266 - 187$	79
$961 - 784$	177
$4977 \div 9$	553
$3732 \div 6$	622
$821 + 428$	1249
$1908 \div 2$	954
$6580 \div 7$	940
72×88	6336
$482 - 419$	63
$3550 \div 5$	710
84×58	4872
$178 + 568$	746
$518 - 221$	297
68×90	6120
$401 + 380$	781
$158 - 106$	52
$2991 \div 3$	997
$2940 \div 4$	735
$932 - 169$	763
$978 + 638$	1616
$314 + 654$	968

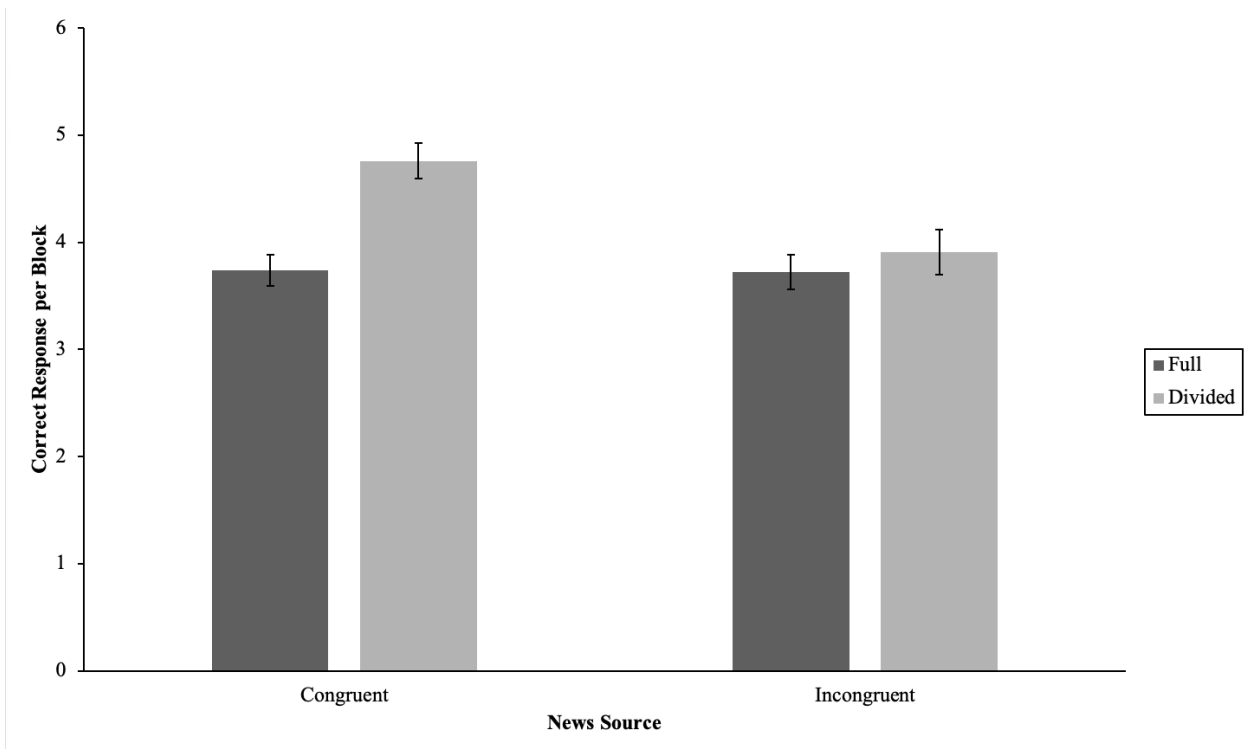
Note. Math problems and their corresponding answers were obtained from Maths Question Generator (Strand: "Number," Topic: "Arithmetic: Four operations," and Difficulty: "4") on MathsBot.com.

Figure 1

Correct Responses per Block for Different Types of News Headlines and News Sources



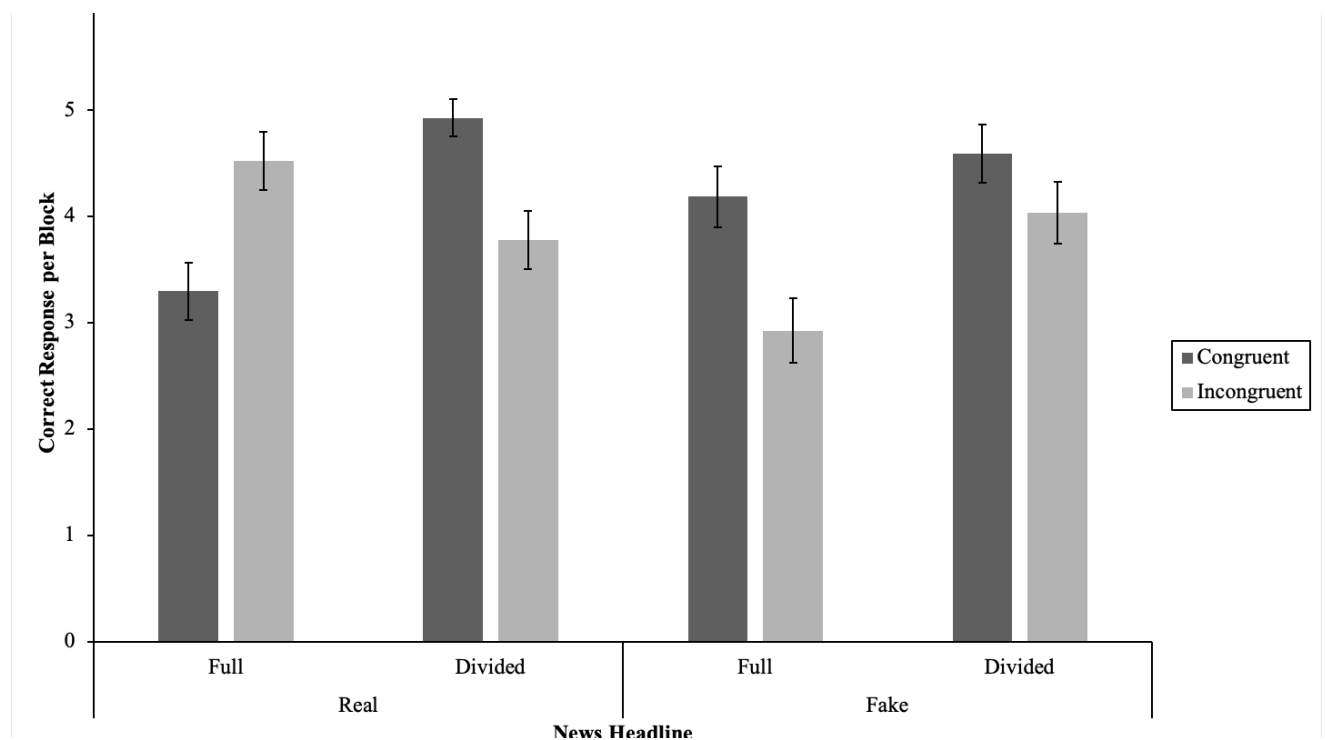
Note. Correct responses per block to congruent and incongruent news sources are shown for real and fake news headlines (error bars show standard errors).



Note. Correct responses per block to congruent and incongruent news sources are shown for full and divided attention (error bars show standard errors)

Figure 3

Correct Responses per Block for Different Types of News Sources, News Headlines, and Attention



Note. Correct responses per block to congruent and incongruent news sources are shown for real and fake news headlines and for full and divided attention (error bars show standard errors).

Appendix

Post-Hoc Interview Questions


1. Did you find that making judgments was generally easy or difficult, or a mix of both?
 - a. What made certain news headlines more difficult/easy to judge?
2. How did you make your decisions about the validity of the news headlines (describe thought process)?
3. Did you consider news sources in your thought process? If so, how?
 - a. Did you use news sources for every news headline, or only the easy/hard ones?
 - b. How did the news sources impact your judgment?
4. Did the math problems make it easier/harder for you to make a news headline judgment?

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Using ArcGIS StoryMaps to prepare learners for fieldwork

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Fieldwork Novelty in Higher Education

As a signature pedagogy within Bioscience and Geography, Environmental and Earth Science (GEES) subjects (Munge et al., 2017), fieldwork can be defined as a first hand experiential learning opportunity, away from the constraints of a classroom setting (Lonergan & Andresen, 1988). Fieldwork promotes the development of professional working communities (Streule & Craig, 2016), where learners enhance their employability skills (Peacock & Bacon, 2018). An equitable teaching tool, fieldwork narrows the awarding gap in marginalised demographic groups (Beltran et al., 2020).

However the declining and variable picture of school biology fieldwork (Tilling, 2018) means that the unfamiliarity of the fieldwork environment within Higher Education Bioscience fieldwork poses a problem to learners. Institutions cannot rely on learners having had extensive fieldwork experience prior to embarking on their Undergraduate degrees. The unfamiliarity of the fieldwork environment can result in cognitive overload and negative affective responses within learners (Cotton & Cotton, 2009).

Blended Learning and the Role of Technology in Addressing Fieldwork Novelty

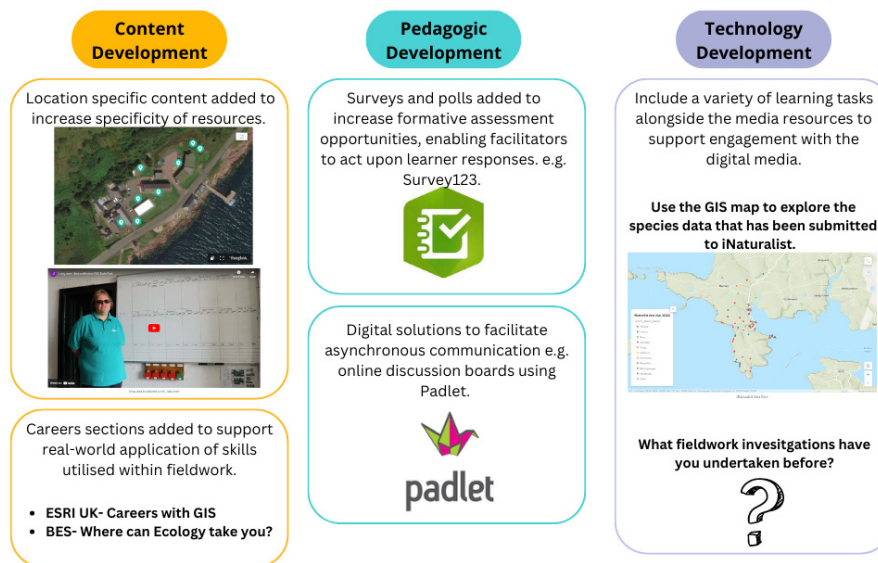
Supporting diverse learners may remove barriers to participation and limit the negative impacts associated with fieldwork novelty. A blended learning approach which utilises virtual introductions prior to fieldwork can enhance learner confidence (Cooke et al., 2020). Although not a silver bullet to all inclusivity challenges, digital preparation could support diverse learners by removing barriers to participation and increase learner knowledge, skills and confidence prior to fieldwork. ArcGIS StoryMaps were chosen as the technology tool to host the digital preparation resources for multiple reasons. Firstly, the platform can host a variety of different data sources (Treves et al., 2021). Secondly, learners find them easy and enjoyable to use (Mukherjee, 2019; Treves et al., 2021). Finally using arcGIS StoryMaps provides opportunities to develop subject specific digital skills such as GIS (Tian et al., 2022).

Utilising Student Voice

This collection of ArcGIS Storymaps was co-designed with learners in a partnership role (McCulloch, 2009). Learners were empowered in an active partnership (Matthews & Dollinger, 2022); which valued co-production at all stages of the development process; from initial conception within the focus groups, to content creation, trialing of the resources and suggestions for further development. Student voice within the process evaluation provided suggestions for technology, content and pedagogic developments. Figure 1 summarises some of the resulting changes made to the resources.

Figure 1

Example of the content, pedagogic and technology developments made to the 'Preparing for Fieldwork' ArcGIS StoryMap resources based on feedback from learners during the process evaluation.



ArcGIS StoryMap Collection

The 'Preparing for Fieldwork' resources provide an opportunity for authentic, immersive integration of classroom and field, an overview and aim are shared in Figures 2a and 2b. Figure 3 is a learner infographic giving details on access and use of the digital resources. The 'Preparing for Fieldwork' collection of StoryMaps have used principles of user-centered design to inform the development of the resources. The resources build on suggestions to address fieldwork novelty through the strengthening of preparation resources (Lang & Persico, 2019; Kingsbury et al., 2020; Lawrence & Dowey, 2022).

Next Steps & Future Research

The 'Preparing for Fieldwork' resources are now ready for learner use prior to their first Higher Education residential at two UK fieldwork locations managed by the Field Studies Council (FSC). The 'Preparing for Fieldwork' resources have been made available to all Higher Education institutions visiting the two fieldwork locations for residential fieldwork. An impact evaluation will be undertaken to investigate how effective these digital preparation resources are in addressing fieldwork novelty and increasing learner confidence in fieldwork. A learner survey will be used before and after the use of the resources, alongside a facilitator of fieldwork survey to capture practitioners' views on the impact of using these resources prior to attending the resi-

dential fieldwork.

These resources present an opportunity for a blended pedagogic approach to fieldwork, where asynchronous digital teaching and learning resources wrap around an in-person fieldwork event, it sits within a wider scope of research assessing the pedagogic benefits of the virtual world to enhance fieldwork learning.

Figure 2a

Overview of the 'Preparing for Fieldwork' digital fieldwork preparation resource.

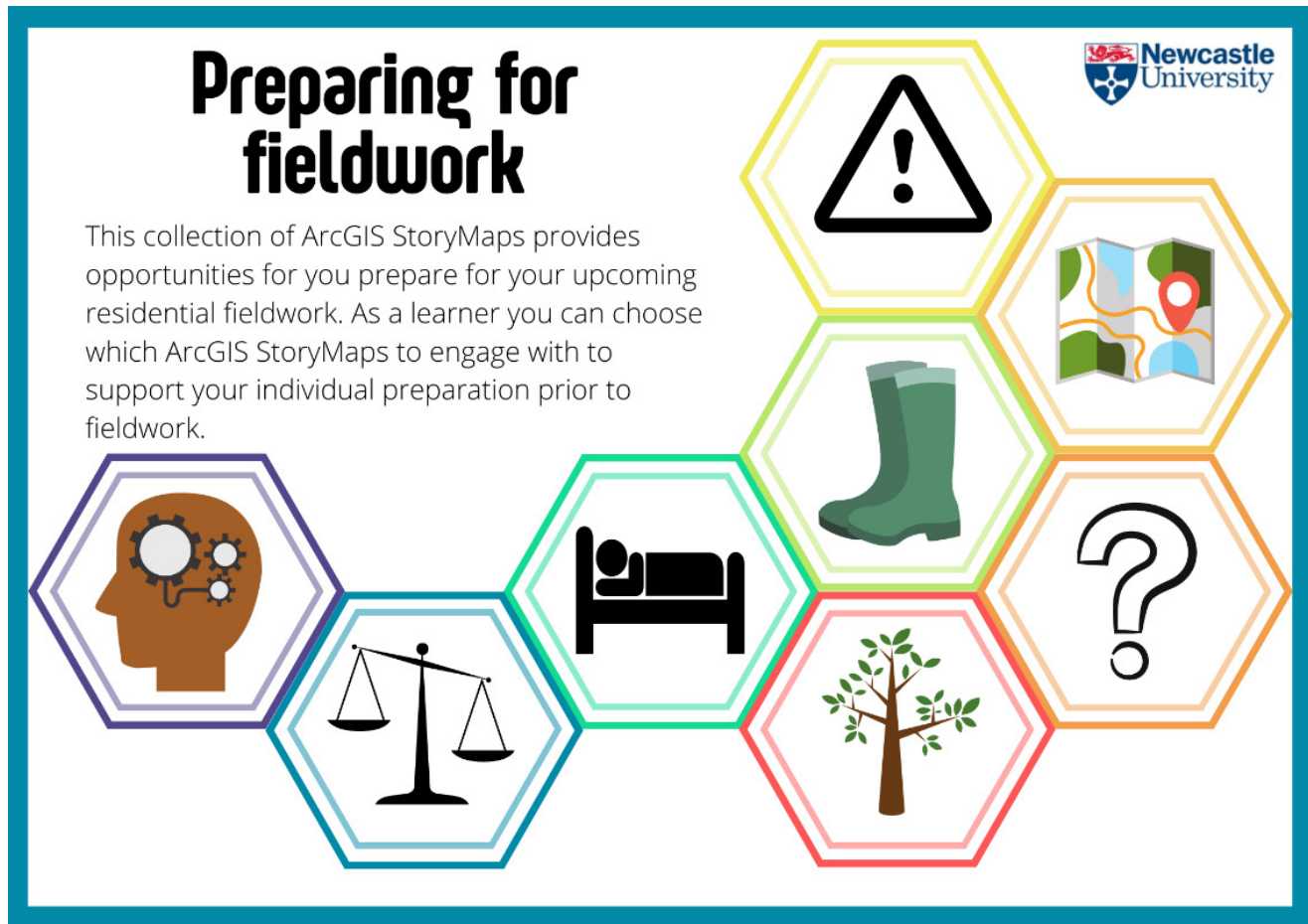


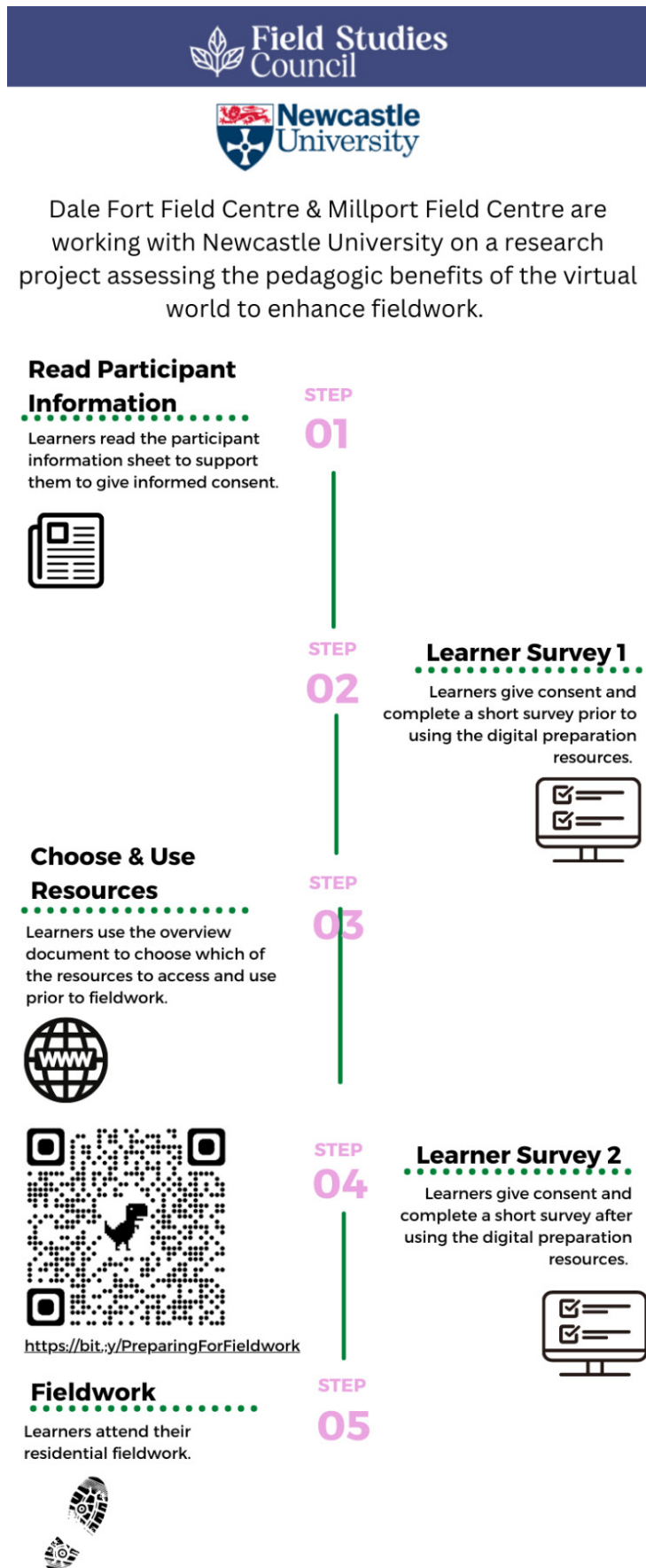
Figure 2b

Aims of each StoryMap within the ‘Preparing for fieldwork’ StoryMap collection.

Health & Safety	Develop an active understanding of the Health and Safety principles and practice that underpin fieldwork.	30-45 mins
Fieldwork Outcomes	What are the outcomes of fieldwork? This will consider the knowledge, skills and personal outcomes that can arise from fieldwork.	15-20 mins
Ethics in Fieldwork	Develop an understanding of the role of ethics in ecological fieldwork and consider the role of an ethical researcher during fieldwork.	15-20 mins
Residential Fieldwork Experience	The logistics, expectations and realities of undertaking residential fieldwork.	20-30 mins
Nature Connectedness	How can being immersed in nature and the outdoors impact you?	15-20 mins
Why fieldwork?	A range of perspectives will be shared on why fieldwork really matters, and what happens to all the fieldwork data that is collected.	20-30 mins
Equipment & Kit	An introduction to some basic fieldwork equipment that you may encounter during ecological fieldwork. Reflections on what your own personal field kit might include with advice on what to pack and bring.	20-30 mins
The Role of Desk Studies	What is the role of research and secondary sources of information in preparing for fieldwork?	30-35 mins

Figure 3

Accessing the 'Preparing for Fieldwork' resources via QR code or weblink.



References

- Beltran, R.S., Marnocha, E., Race, A., Croll, D.A., Dayton, G.H. & Zavaleta, E.S. (2020) 'Field courses narrow demographic achievement gaps in ecology and evolutionary biology', *Ecology and Evolution*, 10(12), pp. 5184-5196.
- Cooke, J., Araya, Y., Bacon, K.L., Bagniewska, J.M., Batty, L., Bishop, T.R., Burns, M., Charalambous, M., Daversa, D.R., Dougherty, L.R., Dyson, M., Fisher, A.M., Forman, D., Garcia, C., Harney, E., Hesselberg, T., John, E.A., Knell, R., Maseyk, K., Mauchline, A.L., Peacock, J., Pernetta, A.P., Pritchard, J., Sutherland, W., Thomas, R.L., Tigar, B., Wheeler, P., White, R.L., Worsfold, N.T. & Lewis, Z. (2020) 'Teaching and learning in ecology: a horizon scan of emerging challenges and solutions', *Oikos*.
- Cotton, D.R.E. & Cotton, P.A. (2009) 'Field biology experiences of undergraduate students: The impact of novelty space', *Journal of Biological Education*, 43(4), pp. 169-174.
- Kingsbury, C.G., Sibert, E.C., Killingback, Z. & Atchison, C.L. (2020) "Nothing about us without us:" The perspectives of autistic geoscientists on inclusive instructional practices in geoscience education', *Journal of Geoscience Education*, 68(4), pp. 302-310.
- Lang, N.P. & Persico, L.P. (2019) 'Challenges and approaches for creating inclusive field courses for students with an autism spectrum disorder', *Journal of Geoscience Education*, 67(4), pp. 345-350.
- Lawrence, A. & Dowe, N. (2022) 'Six simple steps towards making GEES fieldwork more accessible and inclusive', *Area*, 54(1), pp. 52-59.
- Lonergan, N. & Andresen, L.W. (1988) 'Field-Based Education: Some Theoretical Considerations', *Higher Education Research & Development*, 7(1), pp. 63-77.
- Matthews, K.E. & Dollinger, M. (2022) 'Student voice in higher education: the importance of distinguishing student representation and student partnership', *Higher Education*.
- McCulloch, A. (2009) 'The student as co-producer: learning from public administration about the student-university relationship', *Studies in Higher Education*, 34(2), pp. 171-183.
- Mukherjee, F. (2019) 'Exploring cultural geography field course using story maps', *Journal of geography in higher education*, 43(2), pp. 201-223.
- Munge, B., Thomas, G. & Heck, D. (2017) 'Outdoor Fieldwork in Higher Education: Learning From Multi-disciplinary Experience', *Journal of Experiential Education*, 41(1), pp. 39-53.
- Peacock, J. & Bacon, K.L. (2018) 'Enhancing student employability through urban ecology fieldwork', *Higher education pedagogies*, 3(1), pp. 440-450.
- Streule, M.J. & Craig, L.E. (2016) 'Social Learning Theories—An Important Design Consideration for Geoscience Fieldwork', *Journal of Geoscience Education*, 64(2), pp. 101-107.
- Tian, J., Koh, J.H.L., Ren, C. & Wang, Y. (2022) 'Understanding higher education students' developing perceptions of geocapabilities through the creation of story maps with geographical information systems', *British Journal of Educational Technology*, 53(3), pp. 687-705.
- Tilling, S. (2018) 'Ecological science fieldwork and secondary school biology in England: does a more secure future lie in Geography?', *The Curriculum Journal*, 29(4), pp. 538-556.
- Treves, R., Mansell, D. & France, D. (2021) 'Student authored atlas tours (story maps) as geography assignments', *Journal of Geography in Higher Education*, 45(2), pp. 279-297.

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SHORT ESSAY

Embodiment in African Participatory Music Making

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Important Information:

Thank you for showing interest in this interactive essay. The information collected through the activities in this essay are intended for research purposes only, specifically examining the outcomes of the participation in the form of emergent knowledge. The questions marked with an asterisk are mandatory. By participating in the activities your contribution is considered a part of this knowledge and therefore [by completing and submitting this form](#) you will be providing the researcher permission for the aforementioned research. Should you wish to withdraw your participation please contact nk327@exeter.ac.uk

The anticipation was palpable, the curiosity tangible. The participatory seminar on African ways of knowing through music making offered hints of the unknown and unfamiliar.¹ Not only did it offer the opportunity to explore African epistemological and ontological foundations but also to experience it first-hand through music making.² The space was filled with questions, moving bodies, tactile experimentation with objects, and singing voices. Participants present in the room encountered an ‘other’, through the use of their bodies, some in ways they had not previously considered as knowledge production. And this is where this essay draws from - returning to the resources that informed the session (the presentation prepared) and how these resources were reflected in the activities of the session – to extend readers an opportunity to engage similarly in this written format.

¹The seminar on African Ways of Knowing took place at the University of Exeter St Luke’s campus on the 14th of July 2022 through the support of CEEN (Creativity and Emergent Educational Futures) network at the School of Education. It was in collaboration with Blessing Chapfika from the University of Hull, who elaborated on African philosophical principles and was then followed by the author’s enactment of these principles through participatory music making with the participants.

²The use of the term ‘African’ recognises that the continent is made up of diverse peoples and cultures, each with unique ways of being in the continent. Therefore, the term is used loosely to refer to that which emanates from the continent as opposed to racial, socio-cultural or political identifiers commonly associated with the term.

This interactive essay will endeavour to form an understanding of the philosophical framework (why) and praxis (how) of knowledge creation, production and storage in African music making through embodiment. These issues have been a part of the author's PhD thesis that investigates the nexus between African philosophy, music and education in contemporary Kenya. As a music educator and practitioner who worked within that unique context (Kenya), matters of knowledge and its production using the *relevant* theoretical frameworks and the importance of embodiment for knowledge in participatory music making have been of primal interest. Readers are therefore encouraged to actively participate in the activities for better understanding. This new approach to engaging with knowledge opens new methodological ways of engaging with the complex theoretical underpinnings and experiential methodology as regards research especially in African creative arts.

As implied in the introduction to this essay, African ways of being and knowing through the creative arts, and particularly through music and music making, cannot be explored without an understanding of the philosophical underpinnings on which they are based. Here, these underpinnings are explored through the eyes of an East African philosophy called 'Utu'.³ Although a full exploration of this philosophy is beyond the scope of this discussion, the main principles of relationality, connectivity and maturity through transformation are highlighted in the coming section. They will demonstrate why entities of a participatory music event are intricately related. These relationships are enacted through relevant interaction and connection within the music making encounter. The ensuing transformation of, and by, the same entities within that encounter affirm and validate knowledge through the creation of knowledge banks. At the heart of this exploration is the concept of embodiment, which will be defined within the terms of reference highlighted in the philosophical framework already explained.

Because embodiment is better *known* (rather than *known about*) through experience, the reader is invited to participate actively through the links provided for a more visceral engagement with the topic. The links provide an opportunity to enact embodiment in an African music making experience, through observation, performance, composition and reflection. The express disclaimer here is that embodiment by engaging through technology has its own constraints as regards embodiment but it is nonetheless an enabling methodological tool that opens new possibilities beyond restricted time and spaces. The kind of knowledge that emanates from this methodology presents new forms of knowledge (again, this is beyond the scope of this essay) that warrants further consideration. One of those possibilities is that no prior musical knowledge is required for this engagement but the reader's input together with other participants will contribute to a collective body of emergent knowledge for all who participate. Therefore, to begin, please learn the song in Activity 1 below from the Digo Tribe in Kenya. This song will be the basis of all subsequent musical engagements.

³The choice to use the word 'eyes' as opposed to 'lens' is a deliberate positioning of the internal embodied reality of the philosophy in contrast to an externally constructed philosophical framework.

Activity 1: Learning a Senganya song from the Digo Community in Kenya**Song Lyrics**

Heruwa Ee mayo	(A flower, mother)
Heruwa Eee	(A flower)
Heruwa Ramukadi	(A flower from the Ramukadi tree)
Heruwa	(A flower)
Heruwa Ee mayo	(A flower, mother)
Heruwa Eee	(A flower)
Heruwa Ramukadi	(A flower from the Ramukadi tree)
Heruwa Bwaga moyo	(A flower that pleases the heart)

- ❖ Begin by Saying the words as indicated in the audio recording

([AUDIO FILE: Activity 1:1 Learning Heruwa](#))

- ❖ Listen below to the rendition of the song in full, including the responses (in bold)
- ❖ Sing the responses together with the soloist in the recording

([AUDIO FILE: Activity 1:2 Heruwa with responses](#))

Repeat the recording until you are comfortable responding without having to look at the lyrics

Responding with the body

- ❖ Listen to the beat of the song provided by the drum and tap your hand on your RIGHT knee as you sing your responses
- ❖ Now instead of tapping your hand on your knee, hold the same RIGHT knee and lift your leg with the pulse provided.
- ❖ As the song repeats, join in the responses with your movement.

Notice how your entire body responds to this movement (especially your neck, shoulders, waist)

([VIDEO FILE: Activity 1:3](#))

The song in African creative encounters is a primary way of encouraging participation in the community. Through song, both textural and sonic elements are used as tools of communication and expression for philosophical, social, historical and political engagement of the participants. However, songs in most African indigenous communities do not exist in a vacuum, but in a web of integrated artistic performance that is for the most part intentionally participatory. For the purposes of this essay, the description of participatory music making will be informed by

Turino's (2009) definition as 'actively contributing to the sound and motion of a musical event through dancing, singing, clapping and playing musical instruments, when each of these activities is considered integral to the performance' (p. 98). Of particular interest is not necessarily the activities (which will vary depending on the occasion or tribe represented), but how integral and interconnected they are to the encounter. In Activity 2, some of these aspects can be gleaned.

Activity 2: *Identifying Features of a performance*

Open the YouTube links to the following performances in different contexts.

- [Senganya - Digo African Traditional Dance](#)
- [Senganya -Digo \(African Dance\)](#)
- [Kenya traditional dance \(Digo tribe from Mombasa\)](#)

What can you see? What can you hear?

Remember that nothing is insignificant

This is a purely observational exercise and requires no value or meaning attached to the observations. [Put your answers in the padlet board using this code:](#)

CREATING KNOWLEDGE IN PARTICIPATORY MUSIC MAKING

Principles and Participants

In this section we will be briefly exploring some of the theoretical and philosophical principles that inform knowledge production in most African indigenous participatory music making. The principles are based on the understanding that knowledge systems are epistemologically and ontologically considered, as Wane (2005) put it, saying

"In African systems of thought, the ontological position emphasizes that to understand reality is to weave a holistic view of society, that is, to accept the need for harmonious co-existence between nature, culture and society. (p.27)

This suggests that there is an intricate co-existence between life (the people, the environment, the culture, the metaphysical orientations) and human action and experience and one of these experiences is music making. Simply put, the ontological position of music and life in most African contexts is such that music is life and life is music.

To further explain this position, three principles from African thought have been selected for this discussion and these are relationality, connectivity and transformation. Relationality refers to the African cosmological view that all things (physical/nonphysical or tangible/intangible) can be, or become, related based on their similarities, shared spaces or potential. Leopold Senghor (1995) describes this relationship between matter by saying,

'As far as African ontology is concerned, ...there is no such thing as dead matter: every being, every thing -be it only a grain of sand -radiates a life force, a sort of wave-particle; and sages, priests, kings, doctors and artists all use it to help bring the universe to its fulfilment.' (p.49)

Connectivity refers to the **link** that enables related entities and participants to relate, thereby ensuring that exchanges between independent entities exist to transform. Connections create new realities and enact relationships in a cosmic coexistence and without them entities and participants remain mere potentialities. Active contribution to a musical event therefore requires active human participation because participatory performance primarily needs people and aims at connecting people, what Victor Turner (1969, cited by Turino, 2009) called fostering 'Communitas'. Communitas highlights basic sameness, particularly the deep identification of participants as human beings. He says,

'Participatory traditions and events are special in that they are, by nature, the most inclusive and egalitarian; they have the experience of *communitas* as a goal; and they are performance spaces that allow for, actually encourage, everyone to take part in the performance activity regardless of skill level.' (Turino, 2009, p.112, italics by author)

Finally, transformation refers to the **resultant change** that emerges from the interactions and connections in any given space in the form of knowledge. Knowing for the sake of it without any transformational effect or utilitarian significance carries less value in most African indigenous communities because it objectifies and externalises knowledge to human action and experience. Thus, participation in music making (seen as participating in life) transforms and creates knowledge because of encountering the 'other', whether that 'other' bears resemblance to other entities and participants or not. This is particularly so due to the kind of encounter participatory music making is - a neutral, dynamic, temporary, uniquely defined spatial and timebound encounter.

The implication of these principles is that any given life encounter, and by extension, music encounter is a complex interaction of diverse participants, human or otherwise. The individual gives agency and voice to their reality, the community stores cultural and historical knowledge, the environment informs and provides for human action, the abstract holds the liminal spaces of Affect and meaning, and the metaphysical coheres the corporeal realities of the encounter. Therefore, in music making encounters, all participants, seen and unseen play specific roles in knowledge production. In this next activity, return to any of the performances provided and see if you could assign any perceivable roles to the participants.

Activity 3: *Roles of entities and participants.*

Pick any of the features in the performances provided in Activity 2 and assign a role you think they play within the performance. You can pick as many features as you like and [put your comments on this padlet here](#)

It is likely that one single entity or participant has multiple roles. Feel free to suggest as many as you like.

PRODUCING KNOWLEDGE IN PARTICIPATORY MUSIC MAKING

Processes of Embodiment

Given the framework outlined, this discussion is going to turn to how knowledge is produced in most African indigenous communities. It helps to bear in mind that the production and formation of knowledge systems and memory banks in such contexts take a more expansive structure that is not limited to literacy but primarily oral and aural. Gunner (2004) described 'orality' as self-constitutive rather than the absence of literacy, manifesting itself in formal speech and the creative arts in ways that 'empowered social political and spiritual existence' (p. 67). Therefore, as pertains to participatory music making, aurality refers to that which pertains to the *reception* of knowledge through hearing sound. Orality pertains to the *delivery* of knowledge through sound, for instance through song and speech. Literacy pertains to the *use* and *recognition* of knowledge through physical symbols of representation (for instance text, images, objects, as well as nonphysical representations such as sounds, Affect and meaning).⁴ These three processes (reception, delivery and recognition of knowledge) involve sound, particularly the human voice, suggesting that all occur **in relation** to one another through embodiment.

Embodiment has been described in general terms as the tangible or visible representation of an expression or abstraction. This suggests that objects (tangible and intangible) and bodies (human or non-human) can be representations of knowledge. For instance, Loaita (2016) describes embodiment as where the body has been assigned the role of a 'mediator' of 'text' for cultural discourse, image and meaning fits this description. However, it falls short in acknowledging the internal agency of the individual as a participant and the human action they enact. That agency through human action facilitates embodiment of cultural knowledge, which is effectively actualised through the creative arts. That being the case, embodied knowledge requires embodied listening, which according to Gautier (2015), is located 'between the judicial, affective and everyday practices of the disjuncture between the theological and the cosmological, between the rise of a secular order and everyday secularism and between different understandings of "nature"' (p. 212).

Embodied *listening*, which could be broadly taken to mean active listening, is pivotal in the formation of connections between participants of a musical encounter. This listening goes beyond auditory perception but encompasses the full use of other senses and the discernment of other participants and entities of the encounter, especially those with a subtle and nuanced presence (demonstrated for instance in Activity 3 when sounds and images can be embodied when encountered by the reader). When encountering that which is unfamiliar or different in the music encounter, *imitation* with the 'other' aids in connecting to their rhythm (also recognised as their flow) in a gesture of the willingness to share each other's subjectivity. By doing so the belongingness of each entity and participant is affirmed based on what they uniquely bring to the space. The more imitations are *repeated*, the more knowledge from the entities and participants is identified and deemed relevant for the musical encounter. Cor White (2014) described this shared intersubjectivity in embodiment as, 'I know that you know that I know' or 'I feel that you feel that I feel'. In the eyes of Utu it is akin to saying, 'I sense your humanity as you sense mine'.

A musical encounter becomes transformative through the interactions, connections and engagement with both what is known and unknown in a process of *experimentation*. This implies that not all connections are necessary and not all entities belong at the given moment in an encounter. Finding the right 'fit' through experimentation still requires the other tools for embodiment - listening, imitation and repetition - where necessary, making the musical encounter a complex interactive process of embodiment. In addition to experimentation is the process of ex-

⁴The use of 'Affect' in this paper as opposed to 'affect' is linguistically taken as a noun and not a verb. It means that Affect extends in its conceptual use and meaning to encompass emotion and feeling. Of note however, from the theoretical eyes of Utu, it is further understood as the tacit, intuitive and embodied potential that can be expressed physically, socially and spiritually through human action.

tension, which refers to the creative engagement with the connections made within the encounter in new and novel ways and spaces. For instance, one could use an instrument in a manner not conventionally known, or in interaction with others in new encounters.

Sadly, this description of embodiment is difficult to enact in writing and is best experienced in a live participatory musical encounter. Instead, a demonstration of these processes of embodiment in participatory music making is going to be attempted using technology as suggested earlier. Activity 4 provides the reader with an opportunity to experience some of the musical techniques employed in most African indigenous music making practices and includes listening, imitation, repetition, experimentation and extension.

Activity 4: Embedding and Embodying knowledge in Participatory Music Making

LISTENING

The song learnt in Activity 1 will be used here, therefore it may help to refresh your memory by returning to it in the link below

[\(AUDIO FILE: Activity 1:2 Heruwa with responses\)](#)

IMITATING

Now that you remember the song, follow the movements instructed in the video link below. Do what is comfortable and safe for you and if you would like to use more elaborate movement, please feel free to try the movements by the performers referred in the YouTube links provided in Activity 3

[\(VIDEO FILE: Activity 4:1\)](#)

REPEATING

Build layers of performance by internalising the song, then the movement and do both simultaneously. This ensures that whatever role you take in a performance will be secure for the rest of the performers. Train yourself to hold your own part in a stable and steady manner.

[\(VIDEO FILE: Activity 4:2\)](#)

EXPERIMENTATION

When you have internalised the basic principles of the performance you can pick any object, role (instrumental or vocal) or movement and make connections with this given structure derived from one of the performances you have seen in Activity 3

[\(AUDIO FILE: Activity 4:3\)](#)

STORING KNOWLEDGE IN PARTICIPATORY MUSIC MAKING;

Outcomes of the Transformation

Those involved in these processes of music making are transformed to become embodied knowledge bearers through the memory banks that emerge from their experiences. Following Lillestam's (1996) argument therefore that knowledge is stored not only in the brain but also in the body, this implies that entities and participants in the musical encounter become 'text' and 'history'. These texts come in the form of the emergent meaning (both individual and collective), the emergent being (physical and otherwise) and emergent reality that is validated in the lived experiences of the entities and participants. What this means is that the storage of knowledge is not only the prerogative of written texts but also found in the bodies of those who experience the musical encounter and the mediums and tools of expression and communication, specifically the creative arts. This triangulation of the oral, aural and literal, as well as the triangulation through other creative arts and the embodiment of knowledge by the entities and participants fortifies the resilience of knowledge systems and memory banks. With the accumulation of human action, one memory bank is built upon another to form a robust but dynamic system of knowledge and is one of the reasons many indigenous African knowledge systems have remained resilient to this day.

In this final activity you are encouraged to participate in creating a memory bank that will be a part of a knowledge system in this present time. Activity 5 is an experiment in progress that will build with every new participant to the space, accumulating different layers of engagement and contribution. The emergent knowledge will only be fully known in retrospect, but the present invitation determines its outcome.

Activity 5: *Creating memory banks*

EXTENSION

Find a suitable expression that would fit the musical encounter that you have experienced. This can take any form, any language, any form of representation. It is an exercise of individual agency for collective knowledge production. If you would like to contribute, please email nk327@exeter.ac.uk for details of how you can, depending on the form of expression you choose. Every effort will be made to accommodate each contribution and the outcomes of the combined work submitted will be communicated back directly to the participants.

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REFERENCES

- Gautier, A. M. O. (2015). 'Epilogue: The Oral in the Aural'. *Aurality: Listening Knowledge in Nineteenth-Century Colombia*, Duke University Press. <https://www.jstor.org/stable/j.ctv11smfj3.9>
- Gunner, L. (2004). 'Africa and Orality', *The Cambridge history of African and Caribbean literature*, 1, 1-18.
- Lilliestam, L. (1996). 'On Playing by Ear'. *Popular Music*, 15 (2). 195-216
- Senghor, L. (1966). 'Negritude: A Humanism for the Twentieth Century', in F.L Hord and J. S. Lee (Eds.), *I Am Because We are: Readings in Black Philosophy*, published (2016), 45-54. University of Massachusetts Press.
- Turino, T. (2009). 'Four Fields of Music Making and Sustainable Living', *The World of Music*. 51(1), 95–117. <http://www.jstor.org/stable/41699865>
- Wane, N N, (2005), 'African Indigenous Knowledge: Claiming, Writing, Storing, and Sharing the Discourse', *Journal of Thought*, 40 (2), 27- 46 <http://www.jstor.org/stable/42589823> Accessed: 06-12-2016 11:45 UTC

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What is known about the association between Illness Perceptions and Mental Health in Children and Young People with Long-Term Health Conditions: A Scoping Review

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Abstract

Background: Long-Term Conditions (LTCs) are the most common physical illness for children and young people (CYP), with an estimated prevalence of 10-20% of CYP experiencing an LTC. CYP with LTCs are four times more likely to experience a mental health disorder compared to their physically healthy peers. To know how best to support mental health in CYP with LTCs, we need an understanding of potential protective or predictive factors of their mental health. One such factor, which is potentially modifiable, is illness perceptions, yet no review has been undertaken to explore how mental health and illness perceptions interact in CYP with an LTC.

Methods: A scoping review was conducted to investigate what is known about the associations between illness perceptions and mental health in CYP with LTCs. All types of quantitative studies which investigated these associations in any LTC, either cross-sectionally or longitudinally, were included. Psychinfo, Embase, Medline, Web of Science and the Cochrane Library were searched, and a quality assessment completed for all included studies. Two reviewers screened citations for inclusion. Data abstraction was performed by one reviewer. The principles of thematic analysis were applied to the extracted information to synthesise the findings (narrative synthesis).

Results: Thirty-two studies were included (n = 4026 participants), comprised of twenty-five cross-sectional studies and seven longitudinal studies. Studies included a range of LTCs and were from several countries. There was consistent evidence of predominantly moderate and large associations ($r \geq 0.25$), in which more negative illness perceptions associated with worse mental health outcomes. These applied across a range of LTCs, both cross-sectionally and longitudinally.

Conclusions: The consistent evidence of associations between mental health and illness perceptions in CYP with LTCs found in this review, suggests that illness perceptions could be an important factor in how CYP experience their LTC and the co-morbid difficulties around this (i.e., their mental health). Further research is needed to continue to explore this relationship and the potentially modifiable or protective nature of this relationship, to inform future care for individuals with LTCs. Limitations are discussed.

Key Terms: *Children and Young People; Long-term Condition; Illness Perceptions; Mental Health*

Introduction

With advances in paediatric and neonatal care, more children are now surviving disease into adulthood (Nelson et al., 2012; Stoll et al., 2010). An estimated 10-20% of children and young people (CYP) will now experience a long-term condition (LTC; Jin et al., 2017), meaning that LTCs have superseded infectious diseases as the most common physical illness for CYP (Burns et al., 2010). This high prevalence and increased survival mean it is vital to understand the factors associated with CYP's experience of LTCs to better understand their experiences and inform care.

LTCs can have a significant impact on a young person's emotional and social well-being which can affect their daily lives and functioning (Drutchas & Anandarajah, 2014; Fayed et al., 2014). CYP with LTCs are faced with the additional challenges of having to meet the same developmental milestones as their healthy peers (Taylor et al., 2008; Verhoof et al., 2014), while also dealing with and learning to manage their illness (Jedeloo et al., 2010; Nylander et al., 2014). As a result, many experience relational difficulties with their peers (Spencer et al., 2013; Taylor et al., 2008), have lower self-esteem (Pinquart, 2013), may achieve lower grades (Oakley et al., 2020), have a reduced quality of life (cardiac disease; Latal et al., 2009; atopic dermatitis; Ben-Gashir et al., 2004; paediatric sickle cell disease; Mougianis et al., 2020) and are more likely to develop behavioural problems (Gortmaker et al., 1990). CYP with LTCs are also at increased risk of disengaging from their education and having worse educational outcomes (Hopkins et al., 2014; Layte & McCrory, 2013; Thies, 1999), with the impact of these experiences having consequences which continue into adulthood (Juonala et al., 2011).

CYP with LTCs are disproportionately affected by mental health problems. Research estimates that CYP with LTCs are four times more likely to experience a mental health disorder compared to their physically healthy peers (Hysing et al., 2007; Pinquart & Shen, 2011), particularly experiencing anxiety and depression (Akimana et al., 2019; Cadman et al., 1987; Pinquart & Shen, 2011; Pless & Roghmann, 1971; Tesei et al., 2020). While the mechanisms for this increased prevalence are not fully understood (Moore et al., 2019), it is likely that the range of increased challenges CYP with LTCs face could contribute. There is also a long-term impact of this increased prevalence, in which comorbid LTCs and mental health conditions can develop a vicious cycle and exacerbate the other (Cottrell, 2015). Poor mental health is associated with poor treatment adherence, which may exacerbate the physical condition, poor self-management, and worse long-term outcomes (Chavira et al., 2008; Lustman & Clouse, 2005). Research suggests that psychological support for this population is inconsistent, does not always comply with NICE guidelines (Welch et al., 2018) and that services for CYP with LTCs need to better support psychological needs (Barker et al., 2019; Catanzano et al., 2020).

To know how best to support mental health in CYP with LTCs, we need an understanding of potential protective or predictive factors of their mental health. These are factors which may protect an individual from developing mental health difficulties or predict the likelihood of an individual doing so. One such factor, which is potentially modifiable, is illness perceptions – i.e., how someone perceives their illness. Illness perceptions are underpinned by the Common-Sense

Model (CSM) of illness self-regulation (Leventhal et al., 1980; Leventhal, 1984; see Figure 1), which suggested that someone's cognitive and emotional representations of their illness, influence their health outcomes and coping strategies (McAndrew et al., 2019). The model proposed that beliefs about an illness have five core dimensions: cause (the factors an individual believes caused their illness/condition); identity (the label an individual assigns to their illness and the symptoms associated with that label); perceived control (an individual's evaluation of whether strategies are effective and available to control or cure the illness/condition, including both personal control and treatment control); severity of illness consequences (the impact an individual perceives that their illness/condition will have on their life); and timeline (an individual's beliefs about the course of the illness/condition; Moss-Morris et al., 2002). These representations influence how people respond to their illness, both physically and psychologically (Petrie & Weinman, 2006).

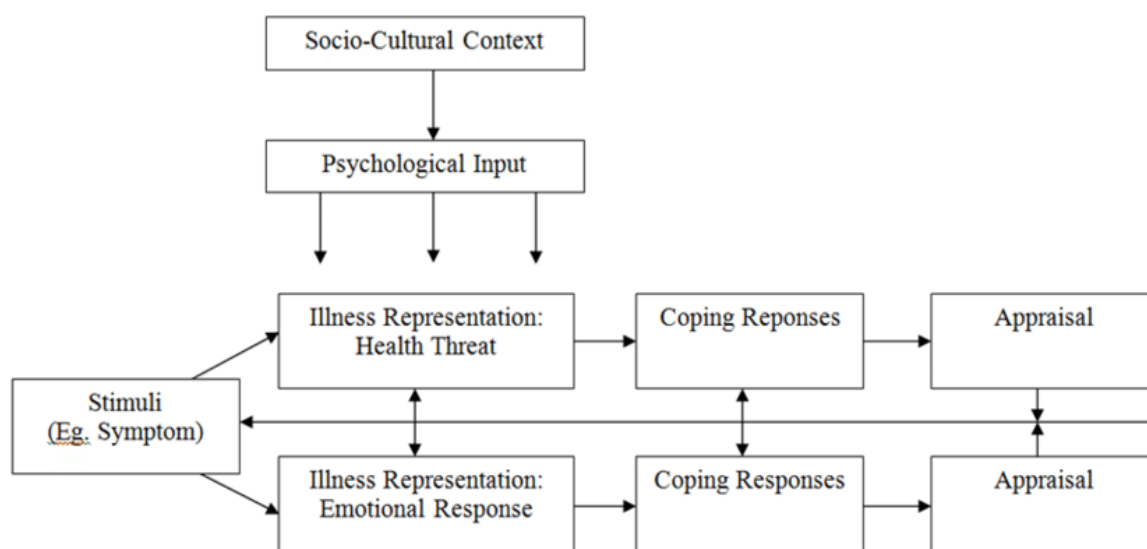


Figure 1 Common-Sense Model (CSM) of Illness Self-Regulation (Leventhal et al., 1980).

Due to the potential significance of illness perceptions in supporting CYP with their mental health, a collation of what is known about the potential effects and associations of illness perceptions in individuals with LTCs is needed. Research has suggested that illness perceptions are an important associating factor (such as within treatment adherence) in several LTCs in CYP (e.g., Diabetes - Wisting et al., 2016; Chronic Fatigue – Haines et al., 2019; Cerebral Palsy – Chong et al., 2012). Closely related factors have also been found to associate with the mental health outcomes of individuals with LTCs (e.g., identity within cancer survivors; Thong et al., 2018). However, while this suggests that illness perceptions may contribute to the mental health outcomes of CYP with LTCs, no review has yet collated what is known about this area.

Due to the increased prevalence of mental health difficulties in CYP with LTCs, it is important to understand whether illness perceptions are consistently related to mental health, both concurrently and over time in CYP with LTCs. While reviews of LTCs in adult populations have identified the importance of illness perceptions in relation to mental health and psychological distress (Arat et al., 2018; Dempster et al., 2015), to date, a review of this area has not been completed in CYP.

Review Questions

This scoping review aimed to summarise the existing evidence about the relationship

between mental health and illness perceptions in CYP with LTCs. Specifically, it addressed the following questions:

- Are illness perceptions associated cross-sectionally with mental health in LTCs?
- Are illness perceptions associated longitudinally with mental health in LTCs (i.e., with mental health as an outcome variable)?
- Where sufficient information exists, this review will compare findings between different LTCs and their associations to mental health.

Method

The scoping review was pre-registered on 22nd October 2020 (<https://osf.io/bh9n2/>). The PICO framework (Richardson et al., 1995), was used to narrow down the aims of this review – specifically the framework helped identify the patient population and outcomes this review was interested in

Children and Young People (CYP) are defined in this review as individuals aged between 4 and 19 years.

Long-Term Conditions (LTC) are defined in this review, as any diagnosed physical health condition (excluding mental health conditions), which has an expected duration of >3 months and for which a cure is considered unlikely. The impact of the condition results in limitations to usual activities and requires an individual to receive medical care or use services beyond what is typical for someone of that age (Moore et al., 2019). A list of chronic illnesses was developed using this definition (see appendices).

Illness perceptions refer to an interaction between someone's cognitive beliefs and emotional representations/responses to their illness (Leventhal, 1984). As such, illness perceptions can be thought of as on a continuum, in that perceptions can range from negative (e.g., I have no control over my illness) to positive (e.g., I have control over my illness) and are commonly measured using quantitative scales (Sawyer et al., 2019). While not limited to, commonly used measures include the Illness Perception Questionnaire (IPQ; Weinman et al., 1996); the Revised Illness Perception Questionnaire (IPQ-R; Moss-Morris et al., 2002), and the Brief Illness Perception Questionnaire (BIPQ; Broadbent et al., 2006).

Studies were included which assessed common aspects of mental health (e.g., anxiety and depressive symptoms), which had been measured by a valid, quantitative assessment method.

Eligibility Criteria

The population is CYP, with a LTC, whose mental health and illness perceptions have also been measured (see Table 1). Studies from any year were included if they met these criteria.

Table 1*Inclusion and Exclusion Criteria*

Inclusion	<ul style="list-style-type: none"> • Peer-reviewed • Reports primary research • Quantitative studies • Sample is predominantly children age ≤ 19 (mean age < 19) or data is separated out for adults and young people • Participants diagnosed with a LTC i.e.: <ul style="list-style-type: none"> • any diagnosed physical health condition, • expected duration of >3 months, • cure is considered unlikely, • results in limitations to usual activities • requires medical care or use of health services beyond what is typical for someone of that age. • Valid assessment of illness perceptions (e.g., questionnaire) • Valid assessment of mental health (e.g., anxiety or depression), or mental wellbeing (e.g., questionnaire/standardised assessment)
Exclusion:	<ul style="list-style-type: none"> • Not published in the English language • Qualitative studies • Unpublished papers/theses • Conference abstracts • Articles that cannot be accessed in full text after reasonable attempts to locate these.

To capture as broad a range of evidence as possible, any study design which met the above criteria (e.g., observational, cohort studies, case-control studies, and clinical trials) were included.

Search Strategy

Five databases were searched for the purpose of this review. Three of these were searched via the search platform OVID: Psychinfo, Embase and Medline. Two of these were individually searched: Web of Science and the Cochrane Library. Collectively, these databases include articles from clinical psychology, health psychology, paediatric and medical journals.

The search terms were initially developed through review of previous literature reviews search terms which had investigated CYP, LTCs, illness perceptions and/or mental health. After review of these search terms, the search strategy followed three stages (Briggs, 2015); an initial preliminary search using the keywords or index terms suggested, a second search using any newly identified keywords or terms, and a final search/screen of the reference lists of identified articles. Searches were completed on July 15th, 2021.

Data extraction and synthesis. The titles and abstracts of all identified studies were screened by the main researcher and by a second screener. The full texts of the remaining pool of studies were then screened by the main researcher. A random selection of these studies (25.9%) was double checked for eligibility by a second screener. At each of these stages, all conflicts were resolved via discussion.

Data was extracted into an excel spreadsheet. This was devised to summarise the data, including authors, country of study, LTCs investigated, sample characteristics, recruitment information, methodology used, the primary research question, the illness perception and mood measure(s) used, the main finding in relation to illness perceptions and mood, and any other findings relevant to illness perceptions.

A spreadsheet was devised to summarise the Newcastle-Ottawa Scale (NOS; Wells et al., 2000) quality assessment, which was completed for each included study. A second screener quality checked, and data extracted two studies to double check the main researcher's decision making.

Initially, frequency analysis was used to identify the number of studies by LTC type or methodology. The principles of thematic analysis were then applied to the extracted information to synthesise the findings, as is advised for scoping reviews (Briggs, 2015). This involved familiarisation with the data and grouping studies by methodology and LTC to identify common themes (Braun & Clarke, 2012; Campbell et al., 2020). Content analysis was used to synthesise the findings by coding the data and identifying themes within these groups (e.g., themes for anxiety or depression). These groupings and themes were initially generated by the lead author and were reviewed by the secondary author. To help synthesise the quantitative associations (reported r values) between studies, associations were determined by effect size: small ($r \geq 0.10$), moderate ($r \geq 0.25$) and large ($r \geq 0.40$; Cohen, 1992). For LTCs with 3 or more studies reporting on them, comparisons were made between the different the LTCs.

Results

The title and abstract of articles retrieved from the searches were screened to determine eligibility (n=11898), 205 of which were full text screened. Of these articles, thirty-two met the full inclusion criteria (see Figure 2).

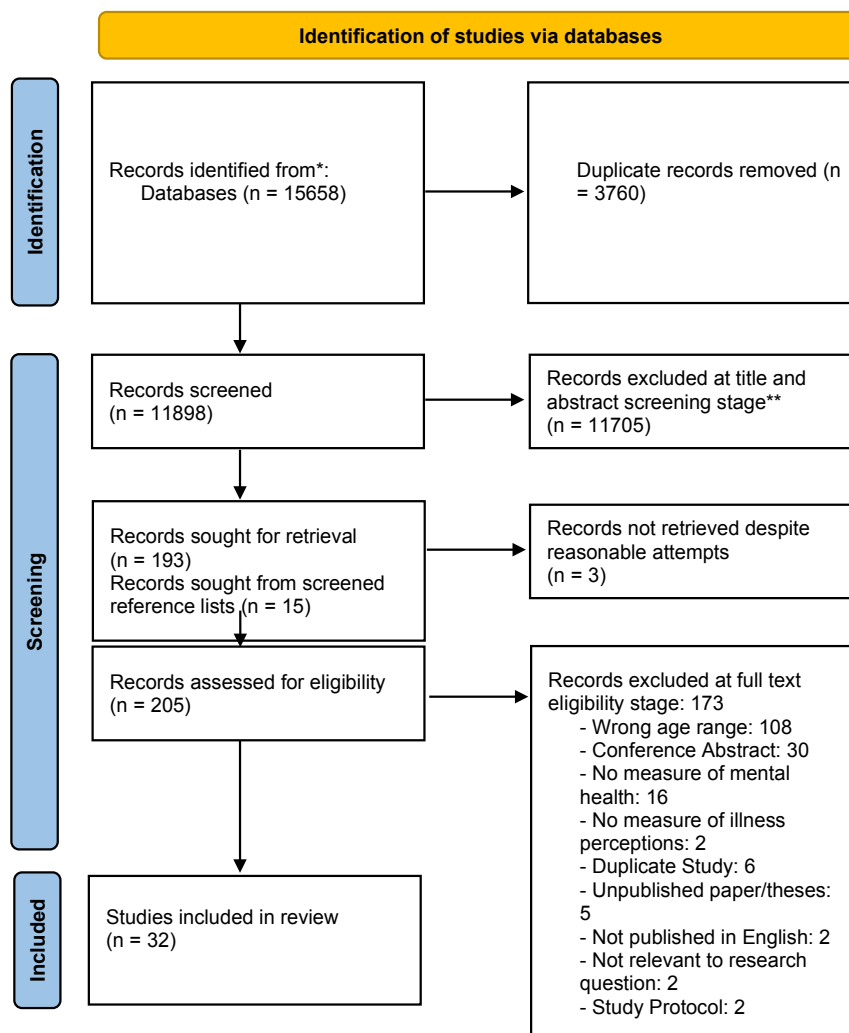


Figure 2 PRISMA diagram for studies identified, screened and included in this review (Page et al., 2021)

These studies that were part of the review included 4026 young people, aged between 8-25 years old. These included both cross-sectional (N=25; see Table 2) and longitudinal studies (N=7; see Table 3). 27 studies included one type of LTC, while 5 studies included multiple LTCs. Most studies were carried out in the USA (N=14), with others were carried out in the UK (N=5), Netherlands (N=3), Australia (N=2), Belgium (N=1), Greece (N=1), Portugal (N=1), Spain (N=1), Nigeria (N=1), Saudi Arabia (N=1), Canada (N=1), and Singapore (N=1).

Quality Assessment

Out of the 32 papers included in this review, 25 were assessed as case control studies (i.e., cross sectional designs) and 7 were assessed as cohort studies (i.e., longitudinal designs). Of the 32 papers, 4 were assessed as being at high risk of bias on the NOS (Molzon et al., 2011; Silva et al., 2018; Valero-Moreno et al., 2020; Williams et al., 2014; see Table 4). This was due

to limitations in participant representativeness, limited use of controls or controlled variables, and exposure determinants (i.e., LTC diagnosis) relying solely on self-report measures without confirming medical records. Therefore, the findings of these studies should be interpreted with additional caution due to the increased risk of these findings not being valid or reliable.

1. Review question 1: Are illness perceptions associated cross-sectionally with mental health in LTCs?

Most cross-sectional studies examined how illness perceptions were associated with anxiety and/or depression (N=21), with two studies reporting associations with psychological distress, and one study each assessing effect on negative affect, and internalising (mood)/externalising (conduct disorder) symptoms. The reported associations have been broken down by LTC.

Type 1 Diabetes (T1D; N=6). Most of the studies investigating T1D found moderate and large associations between illness perceptions and anxiety symptom scores ($r = .30 - .57$). Specifically, the illness perceptions of consequences, personal control, and identity have been consistently associated with anxiety (Law et al., 2002; Williams et al., 2014). Similarly, Williams et al. (2014) found that greater overall negative perceptions of illness consequences were associated with increased depression scores. However, caution should be taken when interpreting the findings from this study due to its high risk of bias. Edgar and Skinner (2003) also found that the perceptions of perceived impact and identity both moderately associated with anxiety and depression scores (i.e., more negative perceptions were associated with increased anxiety symptoms). Both increased psychological distress and more negative illness perceptions (specifically treatment control) have also been found to be largely associated with poorer metabolic control (Goh et al., 2016). The one study assessing negative affect symptoms found that more positive illness perceptions around treatment control mediated the relationship between negative affect symptoms and number of diabetes related problems (Fortenberry et al., 2012).

Contrary to this, there is some evidence in which mental health and illness perceptions do not associate in young people with T1D. Specifically, Law et al. (2002) suggested that illness perceptions did not associate with depressive symptoms but did with anxiety. Group differences in the illness perceptions of CYP with chronic fatigue syndrome, T1D and arthritis, also did not associate with either anxiety or depression score differences (Haines et al., 2019).

Inflammatory Bowel Disease (IBD; N=5). One study investigated anxiety and depressive symptoms and illness perceptions in young people with IBD (Stapersma et al., 2019). They found that specifically within Ulcerative Colitis (and not Crohn's disease), more negative illness perceptions and increased anxiety scores moderately associated with lower health related quality of life (QoL). For depressive symptoms, these associations were large and found in both Crohn's and Ulcerative Colitis patients.

Four studies reported the associations between illness perceptions and depressive symptoms. Silva et al. (2018) demonstrated a significant moderate association between more threatening illness perceptions and increased sadness and depression (However, these findings should be interpreted cautiously due to the study's high risk of bias). Gold et al. (2000) found that a more negative illness perception of IBD as a problem, was largely associated with increased depression scores; and Roberts et al. (2019) found that attitudes around illness uncertainty were mostly moderately associated with depressive symptoms. Contrastingly, one study found that illness perceptions were not significantly associated with the different depressive subtypes found in young people with IBD (Szigethy et al., 2013).

Epilepsy (N=5). All five studies found evidence of moderate and large associations. Sig-

nificant associations were found between total illness perception scores and depression (i.e., more negative attitudes associated with greater depression scores; Wagner et al., 2009), and specifically within epilepsy patients, compared with juvenile rheumatic disease (Ryan et al., 2011). The illness perception of acceptance has also been found to associate with both depressive and anxiety symptom scores (i.e., greater acceptance associated with lower levels of depressive and anxiety symptoms; Engel et al., 2020). Additionally, one study found that more negative illness perceptions moderately associated with increased psychological distress (Rizou et al., 2015) and one study found large associations between more negative illness perceptions, increased internalising and externalising symptoms, and worse school performance (Adewuya et al., 2006).

Sickle Cell Disease and Autoimmune Liver Disease (N=2). In sickle cell disease patients, more negative perceptions of illness related consequences, concerns and emotional responses were largely associated with increased anxiety and depressive scores (Badawy et al., 2017). Similarly, in autoimmune liver disease patients, more negative perceptions of identity, concern and emotional impact were largely associated with greater anxiety scores (Hames et al., 2021). The same study found that alongside these negative perceptions, a negative perception around illness timeline was also largely associated with greater depressive scores.

Allergy (N=2). Two studies have demonstrated significant moderate and large associations between illness perceptions and both anxiety and depressive scores in CYP with allergies. LeBovidge et al. (2009) demonstrated that more negative illness attitudes were associated with increased anxiety and depressive symptoms. Molzon et al. (2011) similarly found that more negative attitudes towards someone's allergy was associated with increased anxiety and depressive symptoms. They additionally found that illness attitudes mediated the relationship between allergy severity and anxiety. However, this study should be interpreted cautiously due to its high risk of bias.

Chronic Arthritis (N=1). The only study of CYP with chronic arthritis (LeBovidge et al., 2005) found that more positive attitudes towards one's illness was significantly largely associated with lower reported anxiety and depressive symptoms. Illness attitudes were also found to moderate the relationship between stress and adjustment to depressive symptoms.

Asthma (N=1). The one study of CYP with asthma (McGrady et al., 2010) found that the association between anxiety and asthma symptoms was partially mediated by illness perceptions. Specifically, the perceptions of consequences, control, and emotional representations mediated this association (i.e., worse perceptions mediating a more negative relationship). There were no studies investigating illness perceptions and depressive symptoms.

Cystic Fibrosis (N=1). The one study of CYP with cystic fibrosis (Leung et al., 1996) demonstrated a large significant positive association between the perception of illness severity and depression scores (i.e., greater perceived severity associated with increased depressive symptoms). There were no studies examining illness perceptions and anxiety symptoms.

Chronic Diseases (N=1). The one study investigating chronic diseases (including chronic respiratory problems; myotonic dystrophy; and short stature in CYP) is a study in which high risk of bias was found (Valero-Moreno et al., 2020). These findings should be interpreted cautiously. This study found that the strongest association with both anxiety and depressive symptomology, was the illness perception of perceived level of illness threat (i.e., increased threat perception was moderately associated with increased anxiety and depressive symptoms).

Ehlers-Danlos Syndrome (N=1). The only study to investigate CYP with Ehlers-Danlos Syndrome found no association between illness perceptions, anxiety or depression and the quality of life of participants (Mu et al., 2018). This was the only LTC in which no associations between illness perceptions and mental health were found by any paper.

Summary. In general, across a range of LTCs, there was consistent evidence of significant cross-sectional associations ($p \leq .05$) between mental health and illness perceptions of at least a moderate effect size.

2. Review Question 2: Are illness perceptions associated longitudinally with mental health in LTCs?

All longitudinal studies examined how illness perceptions were associated with anxiety and/or depression (N=7). These reported associations have been broken down by LTC.

Inflammatory Bowel Disease (N=2). Both studies in IBD reported significant longitudinal associations. Brooks et al. (2019) found that at baseline, all illness perceptions (except timeline) significantly associated at moderate and large levels with both anxiety and depressive symptoms (i.e., more negative perceptions associated with increased anxiety and/or depressive symptom scores). More negative perceptions around illness consequences and emotional impact at baseline moderately and largely associated with increased depressive and anxiety symptom scores at follow-up. More negative perceptions around perceived treatment control at baseline also moderately associated with higher depressive scores at follow-up. Further to these associations, Stapersma et al. (2019) found that disease-specific cognitive-behavioural therapy (CBT), alongside standard medical care, was effective at modifying negative illness perceptions and mental health outcomes. This resulted in improved anxiety and depressive scores and more positive illness perceptions over a 12-month period.

Asthma (N=2). The only study to find significant longitudinal associations in asthma (Tigelman et al., 2014), found that more negative perceptions around perceived concerns, coherence and emotional impact were associated with increased anxiety, depression, and stress symptoms (at small and moderate levels). The same study showed that perceptions of treatment control and emotional impact worsened over time.

Contrastingly, one study reported no associations (Alreshidi et al., 2020). They found that a school-based asthma health program did not improve negative illness attitudes or co-occurring anxiety symptoms following a school-based intervention.

Juvenile Rheumatic Diseases (JRDs; N=1). The one study reporting on JRDs found large significant longitudinal associations with depressive symptoms, but not anxiety symptoms (Ramsey et al., 2012). They found that negative illness attitudes were associated with increased depressive symptoms, and that these negative attitudes preceded variations in depressive symptoms over time (i.e., there were significant longitudinal associations between T1 attitudes and T2 depressive scores).

Type 1 Diabetes (N=1). The one study reporting on T1D, focussed on depressive symptoms (and not anxiety), and found significant longitudinal associations (Rassart et al., 2017). They found that lower illness benefit finding was associated with higher depressive scores. Higher benefit finding at a stable level over time was associated with increased perceptions of personal control; moderate benefit finding at a decreasing level over time was associated with increased perceptions of treatment control; and low benefit finding which continued to decrease over time was associated with more negative views about an illness being cyclical in nature (i.e., perceiving an illness as constant).

Cystic Fibrosis (N=1). The one study reporting on the longitudinal associations in cystic fibrosis found different associations for anxiety and depressive symptoms (Casier et al., 2010). They found that a more positive perception of illness acceptance at baseline was significantly moderately associated to less anxiety symptoms at baseline, but that there was no significant

association over time between acceptance at baseline and anxiety at follow-up. Contrastingly, more positive perceptions of acceptance at baseline were significantly largely associated with less depressive symptoms at baseline and were moderately associated with less depressive symptoms at follow-up.

Summary. In all but one study, across several LTCs, there was consistent evidence of significant longitudinal associations ($p \leq .05$) between mental health and illness perceptions, of at least a moderate effect size. Compared with the cross-sectional evidence, there is fewer longitudinal studies and types of LTCs investigated.

3. Review Question 3: Are there differences in the associations between LTCs and mental health based on the LTC?

Four LTCs (T1D; IBD; Epilepsy; Asthma) had three or more studies reporting on them. Across the different LTCs, most reported significant associations between illness perceptions and mood variables, in which more negative perceptions were related to worse mood outcomes: T1D (6 out of 7 studies); IBD (6 out of 7 studies); Epilepsy (5 out of 5 studies); and Asthma (2 out of 3 studies).

Table 2
Cross-Sectional Study Characteristics and Results

Author (date). Country	Type of LTC	Range (M; SD)	Primary Research Question	IP measure	MH measure	Main findings (in relation to IP and MH)
LeBo- vidge et al. (2005). USA	Chronic arthritis	75 (21; 54)	To identify factors associated with resilience or poor adjustment to chronic arthritis of childhood, with a specific focus on the roles of children's experience of arthritis-related stress and their attitudes toward arthritis.	CATIS	BDI-Y; RC-MAS	<ul style="list-style-type: none"> Attitude toward illness was a significant predictor of child adjustment (more positive attitude associated with lower levels of depressive and anxiety symptoms). Attitude toward illness served as a moderator of the relationship between stress and adjustment in the case of depressive symptoms, with positive attitude demonstrating a protective role against the impact of psychosocial stress. IPs individually correlated with depression ($r = -.67^{***}$), anxiety ($r = -.60^{***}$) and parent rated adjustment ($r = -.28^*$).

<p>McGrady et al. (2010). USA</p>	<p>151 (60; 91) 11-18 (M = 15.8; SD = 1.8)</p>	<p>To examine the possible mediating role of illness perceptions in the anxiety-asthma symptoms relationship in a sample of urban adolescents.</p>	<p>BIPQ</p>	<p>MASC-10</p>	<ul style="list-style-type: none"> The relationship between anxiety symptoms and asthma symptoms was partially mediated by illness perceptions (consequences, control & emotional representation). Higher levels of anxiety were associated with feeling that one's asthma negatively impacted one's life and emotions were difficult to control. These negative illness perceptions, in turn, were related to greater asthma symptoms.
<p>Engel et al. (2020). USA</p>	<p>179 (70; 109) 13-24 (M = 19.2; SD = 3.6)</p>	<p>To (1) describe the prevalence of clinically significant elevations in anxiety and depressive symptoms in a geographically diverse cohort of AYA with epilepsy. (2) examine the relative contribution of demographic and medical characteristics, illness beliefs, and social factors to anxiety and depressive symptoms.</p>	<p>ICQ</p>	<p>GAD-7; PHQ-9</p>	<ul style="list-style-type: none"> In bivariate analyses, five of the eight individual illness perception questions were significantly associated with both increased anxiety and greater asthma-related impairment ($p < .05$): consequences ($r = .38$); timeline ($r = .25$); personal control ($r = -.23$); identity ($r = .21$); and emotional representations ($r = .29$). Acceptance was the only strong predictor of depression and anxiety scores. Individuals with higher levels of acceptance were less likely to report anxiety and depressive symptoms. Correlations between the six illness beliefs and GAD-7 and PHQ-9 scores showed the highest factor correlations were between helplessness with acceptance ($r = 0.6$) and connectedness with helplessness or acceptance ($r = 0.4$).

Leung et al. (1996).	Cystic fibrosis (CF) or insulin-dependent diabetes mellitus (IDDM)	52 (26; 26)	To describe the inter-relationships of chronic illness severity, as perceived by adolescents, with measures of their psychosocial well-being and objective indices of medical severity (biological and physiological effects); 2) to compare the adolescents' perceptions of chronic illness severity with how physicians believe that adolescents perceive the severity of their chronic illness.	PSCI	BDI	<ul style="list-style-type: none"> • A significant positive relationship was found between the adolescents' total perception of illness severity and the Beck Depression Inventory ($r=0.4$, $P < 0.01$). • A significant negative correlation was found between the total perception of illness severity and the Self-Description Questionnaire t-scores ($r = -0.55$, $P < 0.001$). • In IDDM group, no significant relationships were found between adolescents' total PSCI scores and medical measures of illness severity. • The perception of illness severity of the adolescents with CF was significantly correlated with the duration of their illness ($r=0.53$, $P \sim 0.01$).
Wagner et al. (2009).	Epilepsy	77 (35; 42)	To examine self-efficacy for epilepsy management, attitudes toward epilepsy, and hopelessness in children with paediatric epilepsy, which could provide stronger support for a psychosocial model of depressive symptoms as well as specific prospective points of intervention for future mental health treatment programs.	CATIS	CDI	<ul style="list-style-type: none"> • The multivariable linear regression model with CATIS, HSC, and SSES-C was significant ($p < .0001$). • All three independent variables had statistically significant parameter estimates ($p < .05$). On the average, after adjusting for total scores on HSC and SSES-C, the estimated average raw total CDI score is decreased by 3.04 points (95% CI 5.10, 0.97) for each point increase in the average CATIS score mean value (negative attitude = increased depression). • Self-efficacy did not act as a moderator of the relationship between attitude toward illness and depression. • Hopelessness did mediate the effect of attitude toward illness on depressive symptoms after adjusting for self-efficacy.

Badawy et al. (2017). USA	Sickle cell disease (SCD)	34 (20; 14) 12-22 (M = 14.8; SD = 3)	The objectives of this study were to: (1) examine patients' perceptions of SCD and hydroxyurea amongst AYA using the Brief Illness Perception Questionnaire; and (2) explore the relationship of patients' perceptions of SCD and hydroxyurea to their demographic and clinical characteristics, domains of HRQOL and adherence to hydroxyurea.	BIPQ	PROMIS®-CAT measures of depression and anxiety.	<ul style="list-style-type: none"> • Participants with more SCD related consequences, concerns, and emotional response reported worse anxiety ($r = 0.55, p < 0.01$; $r = 0.58, p < 0.001$; $r = 0.56, p < 0.01$), and depression ($r = 0.64, p < 0.001$; $r = 0.49, p < 0.01$; $r = 0.7, p < 0.001$). • Participants with less perceived benefits of hydroxyurea reported worse anxiety ($r = -0.47, p < 0.01$), and depression ($r = -0.62, p < 0.001$). • Median scores indicated that older participants had more positive perceptions of personal control of SCD compared to younger ones, while females perceived more SCD symptoms compared to their male counterparts. An increased number of hospitalizations also associated with worse illness perceptions.
Hames et al. (2021). UK	Autoimmune liver disease (AILD)	68 (31; 37) 15-22 (M=17.9; SD = 1.8)	This study aimed to identify young people with AILD: 1. How well self-reported adherence reflects objective markers of disease status. 2. The factors associated with (non-) adherence and poor treatment response, including clinical characteristics, anxiety and depression, and beliefs about illness.	BIPQ	PHQ-2; PHQ-9; GAD-2; GAD-7	<ul style="list-style-type: none"> • Depression scores sig. positively correlated with timeline, identity, concern, and emotional impact scales (r value ranged from .41 to .50) • Anxiety scores sig. positively correlated with identity, concern, and emotional impact scales (r value ranged from .49 to .50) • Non remission participants expressed more concern about their illness (mean 4.9 vs 4.1, $P < 0.05$) but at the same time a better understanding of their illness and treatment (mean 8.0 vs 6.9, $P < 0.01$) compared to REM group. Illness perceptions were not related to medication adherence.

LeBo- vidge et al. (2009). USA	Food allergy	70 (male/ female not reported) 8-17 (M = 11.2; SD = 2.5)	The primary goals of this study were (1) to assess psychological distress among children with food allergy and (2) to identify factors associated with child distress.	CATIS	BASC-2; MASC	<ul style="list-style-type: none"> • More negative attitudes toward food allergy were associated with greater child-reported anxiety symptoms ($r = -.49^{***}$), depressive symptoms ($r = -.44^{***}$), and social stress ($r = -.33^{**}$) on the BASC-2, as well as anxiety symptoms on the MASC ($r = -.34^{**}$).
Szigethy et al. (2013). USA	Inflamma- tory Bowel Disease (IBD)	226 (105; 121) 9-17 (M = 14.3; SD = 2.42)	To use a person-cen- tered analysis to identify homogeneous groups of youth with IBD who have similar patterns of depressive symptoms and to assess uniquely associated demograph- ic and clinical features.	BIPQ	CDI; CDRS-R; SCARED	<ul style="list-style-type: none"> • Illness perceptions were not significantly associat- ed with depression subtype in individuals with IBD • Illness perceptions did not predict group member- ship.
Law et al. (2002). UK	Type 1 Dia- betes	30 (16; 14) 13-18 (M = 15.5; SD = 1.6)	To explore the relation- ships among illness be- liefs, diabetes self-man- agement behaviours, psychological well-be- ing, and blood-glucose control.	IPQ-R	Well-Being Questionnaire (inc. depres- sion & anxiety subscale)	<ul style="list-style-type: none"> • Illness beliefs components accounted for 52% and 32% of the variance in anxiety ($r = .53^{**}$) and positive well-being, respectively. • Consequences and personal control were signif- icant positive predictors for anxiety and positive well-being, respectively. • Regression analysis found positive well-being to be significantly predicted by both self-manage- ment and illness beliefs. • Prediction of depression and positive well-being was not significantly enhanced by the addition of illness beliefs.

<p>Mu et al. (2018). USA</p>	<p>Ehlers-Danlos Syndrome (EDS)/ Hypermobility Spectrum Disorders (HSD)</p>	<p>47 (9; 38) 10-20 (M = 16.1; SD = 2.9)</p>	<p>This present study aimed to investigate complications, HRQOL predictors and important additional HRQOL factors, such as daily function, sleep, school attendance, sense of wellness, and illness representation, in children and adolescents with EDS/HSD, as perceived by both the affected individuals as well as their parents.</p>	<p>BIPQ</p>	<p>Select questions for anxiety and depression agreed upon via Delphi method.</p> <ul style="list-style-type: none"> • Neither illness perceptions or mental health predicted quality of life in a paediatric and adolescent EDS/HSD population. • In response to what caused their illness, 95% of patient participants reported an intrinsic factor (outside of their realm of control) and 51% reported an extrinsic factor (within their locus of control).
<p>Stappers- ma et al. (2019). Netherlands</p>	<p>Inflammatory Bowel Disease – split into Crohn’s disease (CD) and Ulcerative Colitis and IBD unclassified (UC/IBD-U).</p>	<p>262 (122; 140) 10-20 (M = 16.74; SD = 2.77)</p>	<p>Aims to clarify the association of a combination of psychological factors (illness perceptions, cognitive coping, anxiety, and depression) with HRQOL, over and above demographic and disease factors.</p>	<p>BIPQ CDI; SCARED</p>	<ul style="list-style-type: none"> • In both disease groups, more negative illness perceptions ($\beta = -.412$; $\beta = -.438$, $p < .001$) and more depression ($\beta = -.454$; $\beta = -.279$, $p < .001$) were related to lower HRQOL. • In the UC/IBD-U group, more anxiety was related to lower HRQOL ($\beta = -.201$, $p = .001$). • The model with the psychological variables explained a large and significant amount of variance in both groups: 74% and 83%, respectively ($p < .001$).

Rizou et al. (2015).	Epilepsy	100 (59; 41)	Aimed to explore, apart from demographic and disease characteristics, the role of more malleable determinants such as youngsters' illness perceptions, autonomous motivation towards treatment, and parents autonomy supportiveness on psychological distress and quality of life of youngsters with epilepsy.	BIPQ	RCADS	<ul style="list-style-type: none"> Illness perceptions predict psychological distress. The final model (model 3: $R^2 = 0.436$, adjusted $R^2 = 0.379$, $F = 7.716$, $df = 9$, $P < 0.001$) suggested that believing that epilepsy will last for a long time, feeling that one has less personal control over one's disease, believing that treatment can help, and feeling that epilepsy will have a high emotional impact predict higher levels of distress. Illness perceptions predict QoL (model 3: $R^2 = 0.366$, adjusted $R^2 = 0.303$, $F = 5.77$, $df = 9$, $P < 0.001$). Treatment control and emotional representation were the only significant predictors of quality of life.
Silva et al. (2018).	Inflammatory disease (IBD)	36 (22; 14)	Aims of this study were: <ul style="list-style-type: none"> To describe illness perceptions, distress and well-being of adolescents with IBD. To associate illness perceptions with distress and well-being of adolescents with IBD. 	BIPQ	HBSC	<ul style="list-style-type: none"> Positive statistically significant correlations were found between a more threatening perception of illness and sadness and depression ($r = .376$, $p < .05$). Significant correlations were found between a poorer perception of an illness being a barrier to doing things ($r = .458$, $p < .05$); less satisfaction with life ($r = .587$, $p < .01$); and increased feeling of unhappiness ($r = .498$, $p < .01$). When grouped into two sub-samples on disease activity (active or in remission), statistically significant differences were found in illness perceptions referring to self-control, concern, emotional impact, threat perception, and self-perception of illness as a barrier to do things.

Fortenberry et al. (2012). USA	Type 1 Diabetes	209 (97; 112) 10-15 (M=13.0; SD = 1.54)	The goal of this study was to examine how adolescents' views of diabetes control interfaced with the daily relationship between emotions and diabetes management.	IPQ	A modified version of the Positive and Negative Affect Schedule	<ul style="list-style-type: none"> Negative affect was associated with more self-reported daily diabetes-related problems. Adolescents' perceptions of their treatment's ability to control their diabetes moderated the association between negative affect and number of diabetes-related problems. No moderation affect was found for personal control.
Vale-Moreno et al. (2020). Spain	Chronic diseases (chronic respiratory problems; Myotonic Dystrophy; short stature)	489 (267; 222) 9-16 (M = 12.03; SD = 2.05)	The main objective of the study was to analyze the psychometric properties of BIPQ in a sample of chronically ill adolescents, while studying the dimensionality of the scale and the effect of age, sex and medical diagnosis, and to offer interpretative scales.	BIPQ; IPQ-R	HADS	<ul style="list-style-type: none"> The main predictor of anxiety-depressive symptomatology was the level of perception of illness threat (anxiety: $\beta=0.18$, $p \leq .001$; depression: $\beta=0.20$, $p \leq .001$), followed by age. Significant differences were found between all diagnostic groups ($F=26.09$, $p \leq .001$), with moderate to large effect sizes, with diabetics showing greater threat perception ($M=24.39$, $SD=9.54$) than those with short stature ($M=13.97$, $SD=9.80$, $d=1.08$) and respiratory disease ($M=18.69$, $SD=9.74$, $d=0.59$), and a greater threat perception among respiratory patients with short stature ($d=0.49$).
Adewuya et al. (2006). Nigeria	Epilepsy	73 (46; 27) 12-18 (M = 14.47; SD = 2.10)	The purpose of the present study is to assess the school performance in a population of Nigerian adolescents with epilepsy and examine the variables that correlate with academic difficulties in these adolescents.	CATIS	Caretaker scores for the adolescent on the RAZ.	<ul style="list-style-type: none"> Adolescents' attitude toward the illness ($r = -0.433$; $p < 0.001$) and adolescents internalizing symptoms ($r = -0.618$; $p < 0.001$) and externalizing symptoms ($r = -0.375$; $p = 0.001$) were significantly associated with school performance of adolescents with epilepsy. Predictors of poor overall school performance included both adolescents' attitude toward the illness and adolescents' externalizing symptoms (mood symptoms).

<p>Molzon et al. (2011). USA</p>	<p>Allergy</p>	<p>214 (57; 157) 17-25 (M = 19.52; SD = 1.50)</p>	<p>To investigate the impact of attitude toward illness on psychosocial outcomes in AYAs with allergies.</p>	<p>CATIS</p>	<p>CES-D; SAS</p>	<ul style="list-style-type: none"> • AYAs who reported more severe symptoms had more negative attitudes toward their illness ($t(213) = -3.59, P < .001$) • AYAs with more negative attitudes toward their illness reported more depressive symptoms ($t(213) = -6.44, P < .001$) (95% CI = .56 to 2.34). • AYAs who reported more severe symptoms had more negative illness attitudes ($t(213) = -3.59, P < .001$) • AYAs with more negative attitudes toward their illness reported more anxious symptoms ($t(213) = -6.70, P < .001$). • Illness attitudes mediated the relation between allergy severity and anxious symptoms ($F(3, 210) = 24.36, P < .001$). (95% CI = .52 to 2.23). • Female AYAs reported higher levels of depressive and anxious symptoms and had more negative attitudes toward their illness than male AYAs.
<p>Gold et al. (2000). Canada</p>	<p>Inflammatory Bowel Disease (IBD) and Functional Gastrointestinal Complaints (FGI)</p>	<p>62 (39; 23) 8-18 (M = 12; SD not reported)</p>	<p>(a) What is the mental health profile of children with IBD and FGI? (b) What sociodemographic or variables, if any, are associated with depression, with poor self-concept and/or social maladjustment in this population? (c) Are there significant differences between these two groups on any of the above dimensions of mental health.</p>	<p>Piers-Harris Children's Self-concept Scale</p>	<p>CDI</p>	<ul style="list-style-type: none"> • The only statistically significant with CDI was whether the patient saw his or her illness as a problem ($r = -0.43$; i.e., larger perceived problem = increased depression score). • Only 7 (19%) of the children with IBD stated that their illness was a problem in contrast to 17 (65%) of those with FGI. The latter also perceived themselves to be significantly sicker.

<p>Roberts et al. (2019). USA</p>	<p>Inflammatory Bowel Disease (IBD)</p>	<p>107 (51; 56) 10-18 (M = 14.73; SD = 2.38)</p>	<p>To investigate the role of youth and parent subjective perceptions of illness uncertainty and illness intrusiveness in both youth and parent adjustment outcomes in paediatric IBD.</p>	<p>CUIS; IIS-C</p>	<p>CDI-2</p>	<ul style="list-style-type: none"> Initial partial regression results indicated that youth perceptions of both illness uncertainty and intrusiveness were associated to increased youth depressive symptoms. Subsequent regression analyses revealed that youth uncertainty was more closely associated with youth depressive symptoms (.157**), relative to youth intrusiveness. Youth appraisals of uncertainty and intrusiveness made significant contributions to youth depressive symptoms beyond the influence of both parent illness appraisal variables.
<p>Williams et al. (2014). Australia</p>	<p>Type 1 Diabetes</p>	<p>62 (20; 42) 13-17 (M = 14.6; SD = 1.33)</p>	<p>To examine the role of developmental issues, while controlling for other relevant psychological variables, such as illness beliefs, in adolescents with diabetes.</p>	<p>IPQ</p>	<p>CDI; SCAS</p>	<ul style="list-style-type: none"> Correlation analysis: adolescents who viewed their diabetes as having serious consequences was associated with higher levels of both depression and anxiety. Regression analysis: <ol style="list-style-type: none"> Depression - illness consequences (r=.43) were sig. associated with depression scores. However, there was a non-significant trend for identity to predict depression. Anxiety - sig. model when illness perceptions were added (F(5,50) = 3.43 and p = .01), with identity (r=.23) predicting higher levels of anxiety.

Ryan et al. (2011).	Epilepsy; Juvenile Rheumatic Disease	147 (57; 90)	To explore the relationship of youth age and sex to depressive symptoms and attitudes toward illness in 2 similarly challenging but understudied paediatric chronic illnesses.	CATIS	CDI	<ul style="list-style-type: none"> Youth diagnosed with epilepsy, reported higher depressive symptoms than youth diagnosed with juvenile rheumatic diseases (however, there was a significant group x sex x age interaction). Youth diagnosed with epilepsy, reported more negative attitudes toward their illness than youth diagnosed with a juvenile rheumatic disease. No direct interaction between mood and illness perception reported.
Haines et al. (2019).	Chronic Fatigue Syndrome (CFS); Type 1 Diabetes (T1D); Juvenile Idiopathic Arthritis (JIA)	143 (52; 91)	Aimed to compare illness perceptions across adolescents with CFS, JIA and T1D.	BIPQ	RCADS	<ul style="list-style-type: none"> Group differences in illness perceptions remained even when controlling for fatigue, physical functioning, depression and anxiety. Between-group comparisons on BIPQ subscales identified significant differences in consequences (CFS highest), timeline (T1D highest), personal control (T1D highest), treatment control (T1D highest), identity (CFS highest) and understanding (T1D highest) subscales. There were no significant differences in concern or emotional response subscales.

Edgar & Skinner (2003). UK	Type 1 Diabetes	70 (40; 30) 11-18; Girls (M = 14.1; SD = 2.2); Boys (M = 14.1; SD = 2.0)	Explore the role of coping in the Leventhal et al. (1980) self-regulatory model by testing whether coping mediated the relationships between illness representations and emotional well-being.	DIPQ	Well-being Questionnaire	<ul style="list-style-type: none"> The greater the perceived impact of diabetes, the higher were participants' identity scores (i.e., the more symptoms they reported). The more participants reported using cognitive restructuring as a coping strategy, the less depressive symptomatology was reported. For anxiety, the greater the perceived impact of diabetes (32**) and the higher participants' identity scores (.30**; i.e., the more symptoms they reported), the more anxiety they reported. Treatment effectiveness beliefs mediated the association between cognitive restructuring and positive well-being.
Goh et al (2016). Singapore	Type 1 Diabetes (T1D)	41 (19; 22) 14-20 (M = 16.78; SD = 2.02)	To explore the relationship between self-care, illness perceptions and psychological distress with metabolic control in Singaporean adolescents with T1D.	BIPQ	K10	<ul style="list-style-type: none"> Higher HbA1c levels (worse metabolic control) were associated with lower beliefs in treatment control (rs = -.570, p < .01) and higher levels of psychological distress (r = .422, p < .01). Only general diet and perceived treatment control were significant predictors of HbA1c levels.

Key: AYA – Adolescent and Young Adult; BASC-2 – Behaviour Assessment System for Children; BDI – Beck Depression Inventory; BDI-Y – Beck Depression Inventory-Youth; BIPQ – Brief Illness Perceptions Questionnaire; CATIS – Children and Adolescents' Attitude Towards Illness Scale; CDI – Children's Depression Inventory; CDRS-R – Children's Depression Rating Scale-Revised; CES-D – Centre of Epidemiology Studies Depression Scale; CUJS – Children's Uncertainty in Illness Scale; DIPQ – Diabetes Illness Perception Questionnaire; GAD-2/GAD-7 – Generalised Anxiety Disorder Scale; HADS – Hospital Anxiety and Depression Scale; HBSC – Health Behaviour in School-aged Children Scale; HRQL – Health Related Quality of Life; HSC – Highly Sensitive Child Scale; ICQ – Illness Cognitive Questionnaire; IIS-C – Illness Intrusiveness Scale-Child; IP – Illness Perceptions; IPQ – Illness Perception Questionnaire; IPQ-R – Illness Perception Questionnaire-Revised; IRQ-R – Irritability Questionnaire-Revised; K10 – Kessler Psychological Distress Scale; MASC/MASC-10 – Multidimensional Anxiety Scale for Children; PHQ-9/PHQ-2 – Patient Health Questionnaire; PROMIS-CAT – Patient Reported Outcomes Measurement Information System-Computer Adaptive Tests; PSCI – Perception of Severity of Chronic Illness; RA2 – Rutter's Parent Questionnaire; RCADS – Revised Children Anxiety and Depression Scale; RCMAS – Revised Children's Manifest Anxiety Scale; SAS – Sport Anxiety Scale; SCARED – Screen for Child Anxiety Related Disorders; SCAS – Spence Children's Anxiety Scale; SSES-C – Seizure Self Efficacy Scale for Children and Adolescents; * - p < .05, ** - p < .01.

Table 3
Longitudinal Study Characteristics and Results

Author (date).	Country	Type of LTC	Sample population:		Time points and Primary Research Question	IP measure	MH measure	Main finding (in relation to IP and MH)
			X (Male; Female)	Range (M; SD)				
Ramsey et al (2012).	USA	Juvenile rheumatic diseases (JRDS)	30 (8; 22)	7-18 (M = 12.90; SD = 3.14)	2 time points; 1 year apart; 43% completion rate at T2. Examine the nature of the association between illness-specific appraisals and depressive symptoms in a sample of youths with JRDS.	CATIS	CDI	<ul style="list-style-type: none"> Children's negative attitudes toward illness were reliably associated with increased depressive symptoms ($r=-0.76$). Illness attitudes preceded variations in depressive symptoms over time (individual cross-lagged correlations revealed a significant longitudinal association between Time 1 CATIS and Time 2 CDI (A1D2), $r=-0.76$, $p<.01$).

<p>Casier et al (2010). Belgium</p>	<p>Cystic Fibrosis</p>	<p>40 (23; 17) 14-22 (M = 18.4; SD = 2.87)</p>	<p>2 time points; 6 months apart; 70% completion at T2. To investigate the long-term effects of acceptance on well-being (anxiety, depression & HRQoL).</p>	<p>ICQ (acceptance scale only)</p>	<p>HADS</p>	<ul style="list-style-type: none"> • More acceptance was significantly related to less anxiety symptoms at Time 1 ($r=.29$). However, there were no significant association found between acceptance at Time 1 and anxiety symptoms at Time 2. • More acceptance was significantly related to less depressive symptoms at Time 1 ($r=.65^*$), and less depressive symptoms at Time 2 ($r2=.22^*$). • Acceptance was not related to physical functioning at both time 1 and 2. • More acceptance was related to better role functioning at Time 1, but not Time 2. • More acceptance was related to better emotional functioning at Time 1, but not Time 2. • More acceptance was also related to better social functioning at Time 1, but not Time 2.
<p>Brooks et al (2019). UK</p>	<p>Inflammatory Bowel disease</p>	<p>121 (60; 61) 16-22.7 (Median = 19.33; No M or SD reported)</p>	<p>2 time points; 12 months apart; 83% completion at T2. Aimed to describe the prevalence and severity of psychological morbidity (anxiety, depression HRQoL) over a 12-month period in a UK cohort of young people aged 16–21 years, with IBD. The study also aims to examine relationships between clinical risk factors and illness perceptions, assessed at baseline, and psychological morbidity at baseline and 12-month follow-up.</p>	<p>IPQ-R</p>	<p>HADS</p>	<ul style="list-style-type: none"> • At baseline, all illness perceptions dimensions (except for timeline) were significantly correlated with psychological morbidity (r ranged from -0.22 to 0.66) • Perceived negative consequences of IBD and a greater emotional response to IBD at baseline correlated with follow-up anxiety, depression, and HRQoL. • Treatment control at baseline correlated with follow-up depression and HRQoL and personal control at baseline correlated with follow-up HRQoL (r ranged from -0.21 to 0.43). • Perceived emotional impact was an independent predictor of all measures of psychological morbidity. • Female patients had more negative illness perceptions compared with males. • Patients defined as having active disease compared with those in remission had a greater perceived emotional impact of IBD and a lower perception of personal control.

Stapersma et al (2019). Netherlands	Inflammatory Bowel Disease	70; Care as usual (M = 21); CBT 37 (10; 27)	3 time points; 6 and 12 months; very low attrition rates.	BIPQ	SCARED; HADS; CDI	<ul style="list-style-type: none"> For all outcomes (except sleep problems; $p=.070$), the average effect of time was significant, indicating that over the course of 12 months, youth in both groups had improved on their psychological outcomes (anxiety, depression, HRQOL, social functioning, coping, and illness perceptions). No significant time-group interaction was found for anxiety, depression or illness perceptions (i.e., no group differences over time).
Tiggelman et al (2014). Netherlands	Asthma	261 (155; 106) 10-15 (M = 11.9; SD = 1.0)	3 time points; 1 year and 2 years; 98.5% completion at T2; 96.9% completion at T2.	BIPQ	HADS	<ul style="list-style-type: none"> More perceived concerns about asthma, less coherence, and more perceived influence of asthma on emotional well-being were associated to increased anxiety, depression, stress (r ranged from 0.13 to 0.35). Perceptions of less treatment control and more concern predicted increased emotional problems over time. Perceiving more personal control and attributing fewer complaints to asthma (identity) were associated with better actual asthma control.

Alreshidi et al (2020), Saudi Arabia	Asthma	228 (122; 106) 7-12 (no M or SD reported)	3 time points; 1 month and 3 months; attrition rate below 2%. The aim of the study was to establish the impact of a school-based asthma health education program on outcomes for asthmatic children in KSA as indicated by changes in quality of life, school absences, anxiety, knowledge of asthma, and attitude to asthma.	AAQ	SCAS	<ul style="list-style-type: none"> The intervention showed no significant differences in either attitude or anxiety scores: <ol style="list-style-type: none"> There was no statistically significant differences in the total SCAS score between either pre- or post-test in both groups. Neither the intervention group nor the control group showed any significant change in attitude toward asthma over the three phases of assessment ($p > .05$).
Rassart et al (2017), USA	Type 1 Diabetes	252 (116; 136) 10-14 (M = 12.49; SD = 1.53)	4 times points; every 6 months; attrition rates not reported. The study had four objectives. 1) to chart the development of benefit finding across adolescence. 2) to identify trajectory classes of benefit finding. 3) to examine whether these trajectory classes of benefit finding were related to trajectories of depressive symptoms, self-care, metabolic control, and several illness perceptions. 4) to investigate prospective associations with depressive symptoms, self-care, and metabolic control.	IPQ-R	CDI	<ul style="list-style-type: none"> Depression scores fit the model of benefit finding (lower BF, higher depressive scores). Illness perceptions - no significant differences between the three benefit finding classes for chronicity, consequences, coherence, and emotional representations. However, adolescents in the high stable class reported stronger feelings of personal control; adolescents in the moderate decreasing and high stable classes reported stronger feelings of treatment control; and adolescents in the low decreasing class reported lower views of the illness as being cyclical in nature.

Key: AAQ – Asthma Attitudes Questionnaire; BIPQ – Brief Illness Perception Questionnaire; CATIS – Children and Adolescents’ Attitude Towards Illness Scale; CBT – Cognitive Behavioural Therapy; CDI – Children’s Depression Inventory; HADS – Hospital Anxiety and Depression Scale; HRQOL – Health Related Quality of Life; ICQ – Illness Cognition Questionnaire; IPQ-R – Illness Perception Questionnaire-Revised; SCARED – Screen for Child Anxiety Related Disorders; SCAS – Spence Children’s Anxiety Scale; * - $p < .05$, ** - p

Table 4

Quality Assessment

		CASE CONTROL STUDIES (inc. cross sectional studies)						
		Selection	Comparability	Exposure				
Study	Total Stars (out of 9)	Is the case definition adequate?	4) Definition of Controls	3) Selection of Controls	2) Representativeness of the cases	1) Ascertainment of exposure	2) Same method of ascertainment for cases and controls	3) Non-Response rate
LeBo- vidge et al., 2005	6	✓	✗	✗	✓	✓	✗	✓
McGrady et al., 2010	6	✓	✗	✗	✓	✓	✗	✓
Engel et al., 2020	6	✓	✗	✗	✓	✓	✗	✓
Leung et al., 1996	6	✓	✗	✗	✓	✓	✗	✓
Wagner et al., 2009	6	✓	✗	✗	✓	✓	✗	✓
Badawy et al., 2017	5	✓	✗	✓	✓	✓	✗	✓

	>	>	>	>	>	>	>	>	>	>	>
	X	X	X	X	X	X	X	X	X	X	X
	>	>	>	>	>	X	>	X	X	X	>
	>	>	>	>	>	>	>	>	>	>	>
	X	X	X	X	X	X	X	X	X	X	X
	X	X	X	X	X	X	X	X	X	X	X
	>	>	>	>	>	>	>	>	>	>	>
	>	>	>	>	>	>	X	>	X	>	>
6	6	6	6	6	6	5	6	3	5	4	6
Hames et al., 2021	LeBo-vidge et al., 2009	Szigethy et al., 2013	Law et al., 2002	Mu et al., 2018	Stapersma et al., 2019	Rizou et al., 2015	Silva et al., 2018	Fortenberry et al., 2012	Vale-ro-Moreno et al., 2020	Adewuya et al., 2006	

	>	>	>	>	>	>	>	>
	X	X	X	X	X	X	X	X
	X	>	>	X	>	X	>	>
	>	>	>	>	>	>	>	>
	X	X	X	X	X	X	X	X
	X	X	X	X	X	X	X	X
	X	>	>	X	>	>	>	>
	X	>	>	X	>	>	>	>
3		6	6	3	6	5	6	6
Molzon et al., 2011		Gold et al., 2000	Roberts et al., 2019	Williams et al., 2014	Ryan et al., 2011	Haines et al., 2019	Edgar & Skinner, 2003	Goh et al., 2016

Quality Assessment

COHORT STUDIES (longitudinal)

	Total Stars (out of 9)	Selection	Comparability	Outcome
First Author and year		1) Representativeness of the exposed cohort 2) Selection of the non-exposed cohort 3) Ascertainment of exposure 4) Demonstration that outcome of interest was not present at start of study	1) Comparability of cohorts on the basis of the design or analysis	1) Assessment of outcome 2) Was follow-up long enough for outcomes to occur 3) Adequacy of follow up of cohorts
Ramsey et al., 2012	6	X ✓	✓ ✓	X ✓ X
Casier et al., 2010	5	X ✓	✓ ✓	X ✓ X
Brooks et al., 2019	7	✓ X	✓ ✓	✓ X ✓
Stapert et al., 2019	8	✓ ✓	✓ ✓	X ✓ X
Tiggelman et al., 2014	7	✓ X	✓ ✓	✓ X ✓
Alreshidi et al., 2020	7	✓ ✓	✓ ✓	X ✓ X
Rassart et al., 2017	6	✓ X	✓ ✓	X ✓ X

Red = Risk of bias; * = criteria met to earn point.

Discussion

Overall, this broad scoping review found that more negative illness perceptions have consistently been at least moderately associated, both cross-sectionally and longitudinally (up to two years), with poorer mental health outcomes in CYP with a range of LTCs.

Specifically, this review suggests that illness perceptions and mental health are consistently cross-sectionally associated across a range of LTCs. While this finding is novel in the context of CYP with LTCs, it is consistent with the associations found in adult populations (Arat et al., 2018; Dempster et al., 2015) and suggests that illness perceptions are an important factor for CYP with LTCs as well. This finding is perhaps not surprising due to illnesses perceptions theoretical underpinning (the CSM of illness self-regulation; Leventhal, 1984) which suggests that someone's emotional representation of their illness will influence their health outcomes (McAndrew et al., 2019). Negative emotional representations within illness perceptions may therefore be the important factor which associates with the worse mental health outcomes seen in this review. While causation cannot be established due to the single time-point in which these associations occur, this suggests that the interactions between a CYPs illness perceptions and their mental health may be an important factor in how they experience their LTC. Across the ten LTCs which reported on cross-sectional associations, only one LTC (Ehlers-Danlos Syndrome; Mu et al., 2018) found no association between illness perceptions and mental health. This suggests that the cross-sectional interactions seen between illness perceptions and mental health may be generalisable across a range of LTCs. This cross-sectional understanding suggests that illness perceptions may therefore act as a potential clinical marker when working with CYP with LTCs and provides useful information to inform future longitudinal research to develop from.

Our review also suggests that illness perceptions and mental health are consistently longitudinally associated within several LTCs, with all but one study (Alreshidi et al., 2020), finding significant associations. This suggests that not only do illness perceptions and mental health interact at a single time-point but continue to interact over time. Negative illness perceptions may therefore precede a deterioration in mental health in CYP with LTCs (e.g., within cystic fibrosis; Casier et al., 2010). This is in line with the CSM of illness perceptions, which suggests that someone's cognitive and emotional representations of their illness precede and influence their physical and emotion coping responses (McAndrew et al., 2019) and may explain why negative illness perceptions were therefore found to precede poorer mental health outcomes. This preceding or predictive nature of illness perceptions is important due to the high prevalence of mental health disorders seen in CYP with LTCs (Hysing et al., 2007; Pinguart & Shen, 2011). It suggests that targeting how CYP perceive their LTC early on (i.e., viewing illness perceptions as a modifiable and/or protective factor), may reduce the future likelihood of developing a mental health difficulty. However, it is important to note that due to there only being seven longitudinal studies identified in this review, these suggestions and conclusions are tentative. More research is therefore needed to develop the robustness and generalisability of these findings.

We identified two studies which did attempt to modify illness perceptions and mental health, with mixed effectiveness. Stapersma et al. (2019) reported that disease-specific CBT positively improved both mental health and illness perceptions, while Alreshidi et al. (2020) found that a school-based asthma health program did not improve negative illness attitudes or co-occurring anxiety symptoms. Based on the current evidence, little can therefore be concluded about how to effectively modify negative illness perceptions, to also improve mental health outcomes. However, with an increasing understanding that illness perceptions and mental health are associated in CYP with LTCs (both cross-sectionally and longitudinally), more research is needed. By identifying how to effectively improve illness perceptions, this could then protect CYP with LTCs from experiencing significant mental health difficulties. This could in turn reduce the co-occurring negative impacts of a LTC and mental health difficulties on a CYP (e.g., on school performance; Oakley et al., 2020; or quality of life; Pinguart, 2013).

Strengths and Limitations

A strength of this review is the use of two screeners, which reduces the likelihood of human error and increases the confidence in our findings (Waffenschmidt et al., 2019). Similarly, this review included five databases which maximised the chances of finding all relevant papers and is in line with the range suggested to be optimal (Bramer et al., 2017). Despite this, it is possible that articles may still have been missed due to missed search terms and because this review only included articles written in the English language.

A strength of the studies included in this review is that most were assessed as not being at high risk of bias, meaning that most findings on which this review is based can be reliably interpreted. Due to this review aiming to map and understand a broad range of evidence, we acknowledge that studies that were lower in quality were still included. However, the use of a quality assessment tool was used to inform this risk and the subsequent presentation of our findings. The range of included countries (N=12) is also a strength as this offers wider generalisability and increases the diversity of this review's findings. However, the diversity of the included research remains limited with most studies coming from western, educated, industrialised, rich and democratic cultures (WEIRD; Henrich et al., 2010), demonstrating the need for more diverse future research. The variety of LTCs included (N=12) is an additional strength, however it is worth noting that the greatest evidence lies within four LTCs (T1D; IBD; Epilepsy; Asthma). These four LTCs are among the most common LTCs experienced by CYP which likely explains why research has focussed more on building an understanding in these conditions. However, research is needed to further understand the interaction between illness perceptions and mental health outside of these four LTCs.

There are limitations within the longitudinal studies found in this review. Firstly, the range of time between assessments varied from 3 months to 2 years, which limits how reliably comparisons can be made between studies and reduces the generalisability of the longitudinal findings. This is because time may act as a significant confounding variable which could have impacted on how illness perceptions and mental health associated. Secondly, the studies did not all control for mental health at time 1, which limits the causal understanding of how illness perceptions and mental health associate over time. More longitudinal research is needed to develop this causal understanding and to develop the evidence of how illness perceptions and mental health interact at different time points in CYP with LTCs.

A final limitation of this review is the wide age range used to define CYP (between 4 and 19 years old). Due to the normative cognitive and emotional development that occurs in young people as they transition from childhood to adolescence, it is possible that younger children (e.g., someone aged 5), form and hold illness perceptions about their LTC differently to an adolescent (e.g., someone aged 15). Therefore, caution should be taken when interpreting these results and generalising findings across the CYP age range and suggests more age specific research or reviews would be helpful.

Implications for research and clinical practice

Future research needs to build on the existing evidence base and further explore the associations between mental health and illness perceptions in a range of LTCs. This needs to be done cross-sectionally, particularly focussing on un- and less explored LTCs (e.g., chronic arthritis; N=1) to increase the generalisability of cross-sectional findings across conditions. This also needs to be done longitudinally for several reasons. Firstly, to develop the comparatively small longitudinal evidence base, to better understand how illness perceptions and mental health interact over time, in a range of LTCs. Within this, it may be important to investigate how illness stage may interact with the associations between illness perceptions and mental health. And secondly, to longitudinally investigate the effectiveness of different interventions, targeted at improving

both illness perceptions and mental health. Developing an understanding of how intervention programmes and/or psychological therapies can improve both illness perceptions and mental health in CYP with LTCs will help inform future clinical practice, policy, and guidelines.

Our findings suggest that it is important for clinicians to hold illness perceptions in mind when working with CYP with LTCs. This could be at several levels. Firstly, when using routine outcome measures (ROMs) to ensure illness perceptions are measured in clinical practice. This will make data available for future research and will ensure illness perceptions are identified and monitored as a contributing factor to the experience of a CYPs LTC. Secondly, as suggested within adults (Arat et al., 2018), clinical practice may benefit from thinking about illness perceptions as a potentially modifiable factor and targeting interventions/therapy at improving negative perceptions. This may protect CYPs mental health and protect against the associated difficulties (e.g., reduced quality of life). While more research is required to build this evidence base, our findings also suggest that it is important for clinicians (nurses, consultants, and psychologists) to hold illness perceptions in mind now to support CYPs mental well-being. Illness perceptions can be used to help clinicians understand and formulate CYP with LTCs experiences of anxiety and depressive symptomatology, to then inform their clinical practice.

Conclusion

Consistent evidence of predominantly moderate to large cross-sectional and longitudinal associations was found between negative illness perceptions and poorer mental health outcomes in CYP with LTCs. This suggests that illness perceptions may be an important factor in understanding how CYP experience their LTC and suggests illness perceptions may act as potentially modifiable and or/protective factor against co-morbid mental health difficulties. However, we acknowledge that there are many LTCs which remain un- or less researched, questions remain around the cultural diversity and generalisability of the existing literature, and potentially important areas remain unexplored (e.g., the influence of illness stage). We therefore conclude that while illness perceptions and mental health are associated in CYP across a range of LTCs, further research is needed to continue to explore this relationship and the potentially modifiable nature of this relationship, to inform future care for CYP with a range of LTCs.

Conflicts of interest

Nothing to declare.

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Biography

This research was completed while I was a trainee clinical psychologist at the University of Bath, where I completed my doctorate between September 2019-September 2022. My research interests lie within young people and clinical health. This scoping review aimed to combine these research interests by exploring how illness perceptions and mental health associate in children and young people with long-term conditions.

References

- Adewuya, A. O., Oseni, S. B., & Okeniyi, J. A. (2006). School performance of Nigerian adolescents with epilepsy. *Epilepsia*, 47(2), 415-420. <https://doi.org/10.1111/j.1528-1167.2006.00437.x>
- Akimana, B., Abbo, C., Balagadde-Kambugu, J., & Nakimuli-Mpungu, E. (2019). Prevalence and factors associated with major depressive disorder in children and adolescents at the Uganda Cancer Institute. *BMC cancer*, 19(1), 466. <https://doi.org/10.1186/s12885-019-5635-z>
- Alreshidi, N. M., Livesley, J., Al-Kalaldeh, M., & Long, T. (2020). The Impact of a School-based, Nurse-delivered Asthma Health Education Program on Quality of Life, Knowledge, and Attitudes of Saudi Children with Asthma. *Comprehensive Child and Adolescent Nursing*, 1-15. <https://doi.org/10.1080/24694193.2020.1824033>
- Arat, S., De Cock, D., Moons, P., Vandenberghe, J., & Westhovens, R. (2018). Modifiable correlates of illness perceptions in adults with chronic somatic conditions: A systematic review. *Research in nursing & health*, 41(2), 173-184. <https://doi.org/10.1002/nur.21852>
- Barker, M. M., Beresford, B., Bland, M., & Fraser, L. K. (2019). Prevalence and incidence of anxiety and depression among children, adolescents, and young adults with life-limiting conditions: a systematic review and meta-analysis. *JAMA pediatrics*, 173(9), 835-844. <https://doi.org/10.1001/jamapediatrics.2019.1712>
- Badawy, S. M., Thompson, A. A., Lai, J. S., Penedo, F. J., Rychlik, K., & Liem, R. I. (2017). Adherence to hydroxyurea, health-related quality of life domains, and patients' perceptions of sickle cell disease and hydroxyurea: a cross-sectional study in adolescents and young adults. *Health and quality of life outcomes*, 15(1), 1-10. <https://doi.org/10.1186/s12955-017-0713-x>
- Bramer, W. M., Rethlefsen, M. L., Kleijnen, J., & Franco, O. H. (2017). Optimal database combinations for literature searches in systematic reviews: a prospective exploratory study. *Systematic reviews*, 6(1), 1-12. <https://doi.org/10.1186/s13643-017-0644-y>
- Braun, V., & Clarke, V. (2012). Thematic analysis. <https://psycnet.apa.org/doi/10.1037/13620-004>
- Briggs, J. (2015). The Joanna Briggs Institute reviewers' manual 2015: methodology for JBI scoping reviews. Adelaide, South Australia: The University of Adelaide, 138. Retrieved from: <https://nursing.lsuhs.edu/JBI/docs/ReviewersManuals/Scoping-.pdf>
- Broadbent, E., Petrie, K. J., Main, J., & Weinman, J. (2006). The brief illness perception questionnaire. *Journal of psychosomatic research*, 60(6), 631-637. <https://doi.org/10.1016/j.jpsychores.2005.10.020>
- Brooks, A. J., Norman, P., Peach, E. J., Ryder, A., Scott, A. J., Narula, P., ... & Rowse, G. (2019). Prospective study of psychological morbidity and illness perceptions in young people with inflammatory bowel disease. *Journal of Crohn's and Colitis*, 13(8), 1003-1011. <https://doi.org/10.1093/ecco-jcc/jjz028>
- Burns, K. H., Casey, P. H., Lyle, R. E., Mac Bird, T., Fussell, J. J., & Robbins, J. M. (2010). Increasing prevalence of medically complex children in US hospitals. *Pediatrics*, 126(4), 638-646. <https://doi.org/10.1542/peds.2009-1658>
- Cadman, D., Boyle, M., Szatmari, P., & Offord, D. R. (1987). Chronic illness, disability, and mental and social well-being: findings of the Ontario Child Health Study. *Pediatrics*, 79(5), 805-813. <https://doi.org/10.1542/peds.79.5.805>
- Campbell, M., McKenzie, J. E., Sowden, A., Katikireddi, S. V., Brennan, S. E., Ellis, S., ... & Thomson, H. (2020). Synthesis without meta-analysis (SWiM) in systematic reviews: reporting guideline. *bmj*, 368. <https://doi.org/10.1136/bmj.l6890>
- Casier, A., Goubert, L., Theunis, M., Huse, D., De Baets, F., Matthys, D., & Crombez, G. (2011). Acceptance and well-being in adolescents and young adults with cystic fibrosis: a prospective study. *Journal of pediatric psychology*, 36(4), 476-487. <https://doi.org/10.1093/jpepsy/jsq111>
- Catanzano, M., Bennett, S. D., Sanderson, C., Patel, M., Manzotti, G., Kerry, E., ... & Shafran, R. (2020). Brief psychological interventions for psychiatric disorders in young people with long term phys-

- ical health conditions: a systematic review and meta-analysis. *Journal of Psychosomatic Research*, 136, 110187. <https://doi.org/10.1016/j.jpsychores.2020.110187>
- Chavira, D. A., Garland, A. F., Daley, S., & Hough, R. (2008). The impact of medical comorbidity on mental health and functional health outcomes among children with anxiety disorders. *Journal of developmental and behavioral pediatrics: JDBP*, 29(5), 394. <https://doi.org/10.1097%2FDBP.0b013e-3181836a5b>
- Chong, J., Mackey, A. H., Broadbent, E., & Stott, N. S. (2012). Children's perceptions of their cerebral palsy and their impact on life satisfaction. *Disability and rehabilitation*, 34(24), 2053-2060. <https://doi.org/10.3109/09638288.2012.669021>
- Cohen, J. (1992). Statistical power analysis. *Current directions in psychological science*, 1(3), 98-101. <https://doi.org/10.1111%2F1467-8721.ep10768783>
- Cottrell, D. (2015). Prevention and treatment of psychiatric disorders in children with chronic physical illness. *Archives of Disease in Childhood*, 100(4), 303-304. <http://doi.org/10.1136/archdis-child-2014-307866>
- Dempster, M., Howell, D., & McCorry, N. K. (2015). Illness perceptions and coping in physical health conditions: A meta-analysis. *Journal of psychosomatic research*, 79(6), 506-513. <https://doi.org/10.1016/j.jpsychores.2015.10.006>
- Drutchas, A., & Anandarajah, G. (2014). Spirituality and coping with chronic disease in pediatrics. *Rhode Island Medical Journal*, 97(3), 26. Retrieved from: <http://rimed.org/rimedicaljournal/2014/03/2014-03-26-spirituality-drutchas.pdf>
- Edgar, K. A., & Skinner, T. C. (2003). Illness representations and coping as predictors of emotional well-being in adolescents with type 1 diabetes. *Journal of pediatric psychology*, 28(7), 485-493. <https://doi.org/10.1093/jpepsy/jsg039>
- Engel, M. L., Shanley, R., Scal, P. B., & Kunin-Batson, A. (2021). Anxiety and depressive symptoms in adolescents and young adults with epilepsy: The role of illness beliefs and social factors. *Epilepsy & Behavior*, 116, 107737. <https://doi.org/10.1016/j.yebeh.2020.107737>
- Fayed, N., de Camargo, O. K., Elahi, I., Dubey, A., Fernandes, R. M., Houtrow, A., & Cohen, E. (2014). Patient-important activity and participation outcomes in clinical trials involving children with chronic conditions. *Quality of Life Research*, 23(3), 751-757. <https://doi.org/10.1007/s11136-013-0483-9>
- Fortenberry, K. T., Wiebe, D. J., & Berg, C. A. (2012). Perceptions of treatment control moderate the daily association between negative affect and diabetes problems among adolescents with type 1 diabetes. *Psychology & health*, 27(3), 294-309. <https://doi.org/10.1080/08870446.2011.561925>
- Goh, C. S. Y., Mohamed, A., Lee, Y. S., Loke, K. Y., Wee, H. L., Khoo, E. Y. H., & Griva, K. (2016). The associations of self-care, illness perceptions and psychological distress with metabolic control in Singaporean adolescents with Type 1 Diabetes Mellitus. *Health Psychology and Behavioral Medicine*, 4(1), 1-14. <https://doi.org/10.1080/21642850.2015.1115728>
- Gold, N., Issenman, R., Roberts, J., & Watt, S. (2000). Well-adjusted children: an alternate view of children with inflammatory bowel disease and functional gastrointestinal complaints. *Inflammatory bowel diseases*, 6(1), 1-7. <https://doi.org/10.1097/00054725-200002000-00001>
- Gortmaker, S. L., Walker, D. K., Weitzman, M., & Sobol, A. M. (1990). Chronic conditions, socioeconomic risks, and behavioral problems in children and adolescents. *Pediatrics*, 85(3), 267-276. <https://doi.org/10.1542/peds.85.3.267>
- Haines, C., Loades, M., & Davis, C. (2019). Illness perceptions in adolescents with chronic fatigue syndrome and other physical health conditions: Application of the common sense model. *Clinical child psychology and psychiatry*, 24(3), 546-563. <https://doi.org/10.1177%2F1359104519829796>
- Hames, A., Matcham, F., Makin, I., Day, J., Joshi, D., & Samyn, M. (2021). Adherence, Mental Health and Illness Perceptions in Autoimmune Liver Disease: Looking Beyond Liver Function Tests. *Journal of pediatric gastroenterology and nutrition*, 73(3), 376-384. <https://doi.org/10.1097/MPG.0000000000003119>

- Henrich, J., Heine, S. J., & Norenzayan, A. (2010). Most people are not WEIRD. *Nature*, 466(7302), 29-29. <https://doi.org/10.1038/466029a>
- Hopkins, L., Green, J., Henry, J., Edwards, B., & Wong, S. (2014). Staying engaged: The role of teachers and schools in keeping young people with health conditions engaged in education. *The Australian Educational Researcher*, 41(1), 25-41. <https://doi.org/10.1007/s13384-013-0096-x>
- Hysing, M., Elgen, I., Gillberg, C., Lie, S. A., & Lundervold, A. J. (2007). Chronic physical illness and mental health in children. Results from a large-scale population study. *Journal of Child Psychology and Psychiatry*, 48(8), 785-792. <https://doi.org/10.1111/j.1469-7610.2007.01755.x>
- Jedeloo, S., van Staa, A., Latour, J. M., & van Exel, N. J. A. (2010). Preferences for health care and self-management among Dutch adolescents with chronic conditions: a Q-methodological investigation. *International journal of nursing studies*, 47(5), 593-603. <https://doi.org/10.1016/j.ijnurstu.2009.10.006>
- Jin, M., An, Q., & Wang, L. (2017). Chronic conditions in adolescents. *Experimental and therapeutic medicine*, 14(1), 478-482. <https://doi.org/10.3892/etm.2017.4526>
- Juonala, M., Magnussen, C. G., Berenson, G. S., Venn, A., Burns, T. L., Sabin, M. A., ... & Sun, C. (2011). Childhood adiposity, adult adiposity, and cardiovascular risk factors. *N Engl J Med*, 365, 1876-1885. <https://doi.org/10.1056/NEJMoa1010112>
- Latal, B., Helfricht, S., Fischer, J. E., Bauersfeld, U., & Landolt, M. A. (2009). Psychological adjustment and quality of life in children and adolescents following open-heart surgery for congenital heart disease: a systematic review. *BMC pediatrics*, 9(1), 1-10. <https://doi.org/10.1186/1471-2431-9-6>
- Law, G. U., Kelly, T. P., Huey, D., & Summerbell, C. (2002). Self-management and well-being in adolescents with diabetes mellitus: Do illness representations play a regulatory role?. *Journal of Adolescent Health*, 31(4), 381-385. [https://doi.org/10.1016/S1054-139X\(02\)00397-X](https://doi.org/10.1016/S1054-139X(02)00397-X)
- Layte, R., & McCrory, C. (2013). Paediatric chronic illness and educational failure: the role of emotional and behavioural problems. *Social psychiatry and psychiatric epidemiology*, 48(8), 1307-1316. <https://doi.org/10.1007/s00127-012-0609-3>
- LeBovidge, J. S., Lavigne, J. V., & Miller, M. L. (2005). Adjustment to chronic arthritis of childhood: The roles of illness-related stress and attitude toward illness. *Journal of Pediatric Psychology*, 30(3), 273-286. <https://doi.org/10.1093/jpepsy/jsi037>
- LeBovidge, J. S., Strauch, H., Kalish, L. A., & Schneider, L. C. (2009). Assessment of psychological distress among children and adolescents with food allergy. *Journal of allergy and clinical immunology*, 124(6), 1282-1288. <https://doi.org/10.1016/j.jaci.2009.08.045>
- Leung, S. S., Steinbeck, K. S., Morris, S. L., Kohn, M. R., Towns, S. J., & Bennett, D. L. (1997). Chronic illness perception in adolescence: Implications for the doctor-patient relationship. *Journal of paediatrics and child health*, 33(2), 107-112. <https://doi.org/10.1111/j.1440-1754.1997.tb01010.x>
- Leventhal, H., Meyer, D., & Nerenz, D. (1980). The common sense representation of illness danger. *Contributions to medical psychology*, 2, 7-30. Retrieved from: https://www.academia.edu/259452/The_Common_Sense_Representation_of_Illness_Danger
- Leventhal, H. (1984). Illness representations and coping with health threats.
- Lustman, P. J., & Clouse, R. E. (2005). Depression in diabetic patients: the relationship between mood and glycemic control. *Journal of Diabetes and its Complications*, 19(2), 113-122. <https://doi.org/10.1016/j.jdiacom.2004.01.002>
- McAndrew, L. M., Crede, M., Maestro, K., Slotkin, S., Kimber, J., & Phillips, L. A. (2019). Using the common-sense model to understand health outcomes for medically unexplained symptoms: A meta-analysis. *Health psychology review*, 13(4), 427-446. <https://doi.org/10.1080/17437199.2018.1521730>
- McGrady, M. E., Cotton, S., Rosenthal, S. L., Roberts, Y. H., Britto, M., & Michael, S. Y. (2010). Anxiety and asthma symptoms in urban adolescents with asthma: the mediating role of illness percep-

- tions. *Journal of clinical psychology in medical settings*, 17(4), 349-356. <https://doi.org/10.1007/s10880-010-9214-3>
- Molzon, E. S., Suorsa, K. I., Hullmann, S. E., Ryan, J. L., & Mullins, L. L. (2011). The relationship of allergy severity to depressive and anxious symptomatology: the role of attitude toward illness. *International Scholarly Research Notices*, 2011. <https://doi.org/10.5402/2011/765309>
- Moore, D. A., Nunns, M., Shaw, L., Rogers, M., Walker, E., Ford, T., . . . Shafran, R. (2019). Interventions to improve the mental health of children and young people with long-term physical conditions: linked evidence syntheses. *Health technology assessment (Winchester, England)*, 23(22), 1. <https://doi.org/10.3310%2Fhta23220>
- Moss-Morris, R., Weinman, J., Petrie, K., Horne, R., Cameron, L., & Buick, D. (2002). The revised illness perception questionnaire (IPQ-R). *Psychology and health*, 17(1), 1-16. <https://doi.org/10.1080/08870440290001494>
- Mougianis, I., Cohen, L. L., Martin, S., Shneider, C., & Bishop, M. (2020). Racism and health-related quality of life in pediatric sickle cell disease: roles of depression and support. *Journal of Pediatric Psychology*, 45(8), 858-866. <https://doi.org/10.1093/jpepsy/jsaa035>
- Mu, W., Muriello, M., Clemens, J. L., Wang, Y., Smith, C. H., Tran, P. T., ... & Bodurtha, J. (2019). Factors affecting quality of life in children and adolescents with hypermobile Ehlers-Danlos syndrome/hypermobility spectrum disorders. *American Journal of Medical Genetics Part A*, 179(4), 561-569. <https://doi.org/10.1002/ajmg.a.61055>
- Nelson, K. E., Hexem, K. R., & Feudtner, C. (2012). Inpatient hospital care of children with trisomy 13 and trisomy 18 in the United States. *Pediatrics*, 129(5), 869-876. <https://doi.org/10.1542/peds.2011-2139>
- Nylander, C., Seidel, C., & Tindberg, Y. (2014). The triply troubled teenager—chronic conditions associated with fewer protective factors and clustered risk behaviours. *Acta Paediatrica*, 103(2), 194-200. <https://doi.org/10.1111/apa.12461>
- Oakley, N. J., Kneale, D., Mann, M., Hilliar, M., Dayan, C., Gregory, J. W., & French, R. (2020). Type 1 diabetes mellitus and educational attainment in childhood: a systematic review. *BMJ open*, 10(1), e033215. <http://doi.org/10.1136/bmjopen-2019-033215>
- Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., ... & Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ*, 372. <https://doi.org/10.1186/s13643-021-01626-4>
- Petrie, K., & Weinman, J. (2006). Why illness perceptions matter. *Clinical Medicine*, 6(6), 536. <https://doi.org/10.7861%2Fclinmedicine.6-6-536>
- Pinquart, M., & Shen, Y. (2011). Depressive symptoms in children and adolescents with chronic physical illness: an updated meta-analysis. *Journal of pediatric psychology*, 36(4), 375-384. <https://doi.org/10.1093/jpepsy/jsq104>
- Pinquart, M. (2013). Self-esteem of children and adolescents with chronic illness: a meta-analysis. *Child: care, health and development*, 39(2), 153-161. <https://doi.org/10.1111/j.1365-2214.2012.01397.x>
- Pless, I. B., & Roghmann, K. J. (1971). Chronic illness and its consequences: Observations based on three epidemiologic surveys. *The Journal of pediatrics*, 79(3), 351-359. [https://doi.org/10.1016/S0022-3476\(71\)80141-5](https://doi.org/10.1016/S0022-3476(71)80141-5)
- Ramsey, R. R., Bonner, M. S., Ryan, J. L., Mullins, L. L., & Chaney, J. M. (2013). A prospective examination of attitudes toward illness and depressive symptoms in youth with juvenile rheumatic diseases. *Journal of Developmental and Physical Disabilities*, 25(2), 171-180. <https://doi.org/10.1007/s10882-012-9294-0>
- Rassart, J., Luyckx, K., Berg, C. A., Oris, L., & Wiebe, D. J. (2017). Longitudinal trajectories of benefit finding in adolescents with Type 1 diabetes. *Health Psychology*, 36(10), 977. <https://psycnet.apa.org/doi/10.1037/hea0000513>

- Richardson, W. S., Wilson, M. C., Nishikawa, J., & Hayward, R. S. (1995). The well-built clinical question: a key to evidence-based decisions. *Acp j club*, 123(3), A12-A13. Retrieved from: <https://asset-pdf.scinapse.io/prod/1572319397/1572319397.pdf>
- Rizou, I., De Gucht, V., Papavasiliou, A., & Maes, S. (2015). Illness perceptions determine psychological distress and quality of life in youngsters with epilepsy. *Epilepsy & Behavior*, 46, 144-150. <https://doi.org/10.1016/j.yebeh.2015.03.022>
- Roberts, C. M., Gamwell, K. L., Baudino, M. N., Perez, M. N., Delozier, A. M., Sharkey, C. M., ... & Chaney, J. M. (2019). Youth and parent illness appraisals and adjustment in pediatric inflammatory bowel disease. *Journal of Developmental and Physical Disabilities*, 31(6), 777-790. <https://doi.org/10.1007/s10882-019-09678-0>
- Ryan, J. L., Ramsey, R. R., Fedele, D. A., Wagner, J. L., Smith, G., & Chaney, J. M. (2012). Exploration of age and sex differences in depressive symptoms and illness attitudes for youth with epilepsy and juvenile rheumatic disease. *Journal of child neurology*, 27(8), 1004-1010. <https://doi.org/10.1177%2F0883073811431109>
- Sawyer, A. T., Harris, S. L., & Koenig, H. G. (2019). Illness perception and high readmission health outcomes. *Health Psychology Open*, 6(1), 2055102919844504. <https://doi.org/10.1177%2F2055102919844504>
- Silva, V., Lima, L., & Lemos, M. (2018). Illness perceptions of adolescents with inflammatory bowel disease and the association with distress and well-being. *Suplemento Digital Revista ROL Enfermería*, 41(11-12), 263-268. <https://doi.org/10.1177%2F2055102919844504>
- Spencer, J. E., Cooper, H. C., & Milton, B. (2013). The lived experiences of young people (13–16 years) with Type 1 diabetes mellitus and their parents—a qualitative phenomenological study. *Diabetic Medicine*, 30(1), e17-e24. <https://doi.org/10.1111/dme.12021>
- Stapersma, L., van den Brink, G., van der Ende, J., Bodelier, A. G., van Wering, H. M., Hurkmans, P. C., ... & Utens, E. M. (2019). Illness perceptions and depression are associated with health-related quality of life in youth with inflammatory bowel disease. *International Journal of Behavioral Medicine*, 26(4), 415-426. <https://doi.org/10.1007/s12529-019-09791-6>
- Stapersma, L., van den Brink, G., van der Ende, J., Szigethy, E. M., Groeneweg, M., de Bruijne, F. H., ... & Utens, E. M. (2020). Psychological outcomes of a cognitive behavioral therapy for youth with inflammatory bowel disease: results of the HAPPY-IBD randomized controlled trial at 6-and 12-month follow-up. *Journal of clinical psychology in medical settings*, 27(3), 490-506. <https://doi.org/10.1007/s10880-019-09649-9>
- Stoll, B. J., Hansen, N. I., Bell, E. F., Shankaran, S., Laptook, A. R., Walsh, M. C., ... & Kennedy, K. A. (2010). Neonatal outcomes of extremely preterm infants from the NICHD Neonatal Research Network. *Pediatrics*, 126(3), 443-456. <https://doi.org/10.1542/peds.2009-2959>
- Szigethy, E. M., Youk, A. O., Benhayon, D., Fairclough, D. L., Newara, M. C., Kirshner, M. A., ... & DeMaso, D. R. (2014). Depression subtypes in pediatric inflammatory bowel disease. *Journal of pediatric gastroenterology and nutrition*, 58(5), 574. <https://doi.org/10.1097%2FMPG.0000000000000262>
- Taylor, R. M., Gibson, F., & Franck, L. S. (2008). The experience of living with a chronic illness during adolescence: a critical review of the literature. *Journal of clinical nursing*, 17(23), 3083-3091. <https://doi.org/10.1111/j.1365-2702.2008.02629.x>
- Tesei, A., Nobile, M., Colombo, P., Civati, F., Gandossini, S., Mani, E., ... & D'Angelo, G. (2020). Mental health and coping strategies in families of children and young adults with muscular dystrophies. *Journal of Neurology*, 267(7), 2054-2069. <https://doi.org/10.1007/s00415-020-09792-6>
- Thies, K. M. (1999). Identifying the educational implications of chronic illness in school children. *Journal of school health*, 69(10), 392-397. <https://doi.org/10.1111/j.1746-1561.1999.tb06354.x>
- Thong, M. S., Wolschon, E. M., Koch-Gallenkamp, L., Waldmann, A., Waldeyer-Sauerland, M., Pritzkuleit, R., ... & Zeissig, S. R. (2018). “Still a cancer patient”—Associations of cancer identity with patient-reported outcomes and health care use among cancer survivors. *JNCI cancer spectrum*, 2(2), pky031. <https://doi.org/10.1093/jncics/pky031>

- Tiggelman, D., van de Ven, M. O., van Schayck, O. C., Kleinjan, M., & Engels, R. C. (2014). The Common Sense Model in early adolescents with asthma: Longitudinal relations between illness perceptions, asthma control and emotional problems mediated by coping. *Journal of psychosomatic research*, 77(4), 309-315. <https://doi.org/10.1093/jncics/pky031>
- Valero-Moreno, S., Lacomba-Trejo, L., Casaña-Granell, S., Prado-Gascó, V. J., Montoya-Castilla, I., & Pérez-Marín, M. (2020). Psychometric properties of the questionnaire on threat perception of chronic illnesses in pediatric patients. *Revista latino-americana de enfermagem*, 28. <https://doi.org/10.1590/1518-8345.3144.3242>
- Verhoof, E. J., Maurice-Stam, H., Heymans, H. S., Evers, A. W., & Grootenhuis, M. A. (2014). Psychosocial well-being in young adults with chronic illness since childhood: the role of illness cognitions. *Child and adolescent psychiatry and mental health*, 8(1), 12. <https://doi.org/10.1186/1753-2000-8-12>
- Waffenschmidt, S., Knelangen, M., Sieben, W., Bühn, S., & Pieper, D. (2019). Single screening versus conventional double screening for study selection in systematic reviews: a methodological systematic review. *BMC medical research methodology*, 19(1), 1-9. <https://doi.org/10.1186/s12874-019-0782-0>
- Wagner, J. L., Smith, G., Ferguson, P. L., Horton, S., & Wilson, E. (2009). A hopelessness model of depressive symptoms in youth with epilepsy. *Journal of Pediatric Psychology*, 34(1), 89-96. <https://doi.org/10.1093/jpepsy/jsn052>
- Weinman, J., Petrie, K. J., Moss-Morris, R., & Horne, R. (1996). The illness perception questionnaire: a new method for assessing the cognitive representation of illness. *Psychology and health*, 11(3), 431-445. <https://doi.org/10.1080/08870449608400270>
- Welch, A., Shafran, R., Heyman, I., Coughtrey, A., & Bennett, S. (2018). Usual care for mental health problems in children with epilepsy: A cohort study. *F1000Research*, 7. <https://doi.org/10.12688/f1000research.15492.2>
- Wells, G. A., Shea, B., O'Connell, D., Peterson, J., Welch, V., Losos, M., & Tugwell, P. (2000). The Newcastle-Ottawa Scale (NOS) for assessing the quality of nonrandomised studies in meta-analyses. Retrieved from: <https://pdfs.semanticscholar.org/5b63/3ae0fca9ba9ddb97b4c35b8c3b264fd5104a.pdf>
- Williams, C., Sharpe, L., & Mullan, B. (2014). Developmental challenges of adolescents with type 1 diabetes: The role of eating attitudes, family support and fear of negative evaluation. *Psychology, health & medicine*, 19(3), 324-334. <https://doi.org/10.1080/13548506.2013.808750>
- Wisting, L., Bang, L., Natvig, H., Skrivarhaug, T., Dahl-Jørgensen, K., Lask, B., & Rø, Ø. (2016). Metabolic control and illness perceptions in adolescents with type 1 diabetes. *Journal of diabetes research*, 2016. <https://doi.org/10.1155/2016/3486094>

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Can Project Management Methodologies in International Development Agencies Be Of Interest To Local Interventionist Agencies in Sub-Saharan Africa

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Abstract

International development agencies (IDAs) and Non-Governmental Organisations (NGOs) execute projects in some countries with the view to alleviate poverty where the projects are to be domiciled, ensure development, amongst stakeholders. Subsequently, over the years researchers have viewed such projects to be successful when x-rayed under the prism of the various derived Project Management Methodologies (PMMs)/tools by Project Managers in the organizations to monitor the projects. Unfortunately, researchers were silent on what made the tools effective. To bridge this gap, and to understand the role of PMMs in project monitoring in IDAs and NGOs, this study review and synthesises the little existing research evidence through a systematic literature review. A range of peer reviewed journal articles between 2010 and 2020 (inclusive) that address the application of PMMs/tools in project monitoring in IDAs/NGOs was systematically assessed. Based on inclusion and selection criteria, 10 eligible articles were selected for final review. It was revealed that there had been different adaptations of the Logical Framework (LF), and the Logical Framework Approach (LFA) used in IDAs/NGOs for project monitoring in the respective IDAs/NGOs, the study also revealed how the updated/adapted LF were made compatible with today's project management tools, making project monitoring in IDAs/NGOs effective. Consequently, the study aimed at evaluating the frameworks, its evolutions from various researchers' paradigms. The objective is to establish some level of awareness and utilization of PMMs/tools for the benefit of researchers, students, and stakeholders in the construction industry.

Keywords: Non-Governmental Organizations, Tools, Project Managers, Local Development Agencies.

Introduction

International Development (ID) agencies like the World Bank, the United Nations and the European Union undertake projects in developing countries, and through fitting Project Management Methodologies (PMMs) deployed by knowledgeable Project Managers (PMs') complete its projects (Golini, Corti and Landoni, 2017) but Local Interventionist Agencies (LIAs) in some Sub-Saharan Africa abandon theirs at different stages of the project life cycle (Eze, 2014).

Admittedly, citing projects in any society are to improve living conditions of the populace. It is also to accelerate growth in physical infrastructures and provide services critical for human endeavours (Ingwe et al., 2012). Eze (2014) asserted that "A greater level of sustainable projects can be achieved if suitable projects are well formulated, prepared and implemented through the instrumentality of government machinery" and this was corroborated by (Oladipo, 2008); he emphasised that projects chosen should be of high priority and widespread acceptability in the national development plan. In that regard, acceptable project monitoring methods should be put in place for better impact assessment, frugal accounting systems and to guide the project from conception to the end of the project life cycle Golini, Corti and Landoni (2017).

This position is in line with the ID agencies, they fund projects across the world mostly in the developing countries, developed and deploy some specific methodologies, notably the Project Cycle Management (PCM) and Logical Framework (LF) and according to Golini, Corti and Landoni (2017, p 129) the objective is to "efficiently carry out social impact assessment and project execution". Thus, a greater number of these projects turn out to be successfully completed and have positively impacted the lives of the target beneficiaries (*ibid*).

Additionally, ID agencies deploy tailored PMM on their projects to meet stakeholders' expectations, according to Khang and Moe (2008), including the funding agencies, the implementing units, and the beneficiaries. Hence a well-suited framework with knowledgeable PMs' to monitor ID projects is needed in order to meet the expectations of the stakeholders. Regrettably, Eze (2014) stated that in some developing countries there are some government interventionist agencies that undertake construction projects, but these projects are poorly delivered or abandoned at different stages of the project life cycle. The projects are sometimes formulated by these agencies without taking into cognisance how the project would either be administered or assess its impacts to the target beneficiaries, this gap enabled corruption, non-accountability, and subsequent project abandonment (Eze 2014, Inigwe et al., 2012). The import of Eze's (2014), Golini, Corti and Landoni (2017) and Ozmen (2013) scholarly work revealed there was a nexus between lack of PMMs on projects and project abandonment.

For instance, report of the recent forensic audit of the Niger Delta Development Commission (NDDC) an interventionist agency in Nigeria, between 2001 and 2019 revealed over 13,777 projects were compromised and abandoned (Malami, 2021). The same thing occurred with several other Local Interventionist' Agencies (LIAs) in Nigeria due to weak supervisory process, and non-adherence to known Project Management process or framework by project administrators in the various agencies (Eze,2014).

The non-realization of projects in Nigeria due to abandonment has resulted in disappointment to the communities in addition to reduction in the standard of living, wastage of resources by the agencies concerned, reduction in employment which hitherto the projects could have sustained, decrease in the tempo of economic activities, decrease in revenue accruing to the government, difficulties in attracting foreign loans/investors (Ayodele, et al., 2011). This was further upheld by a study by Michael et al. (2011) that sees the effect of project abandonment as depriving the populace access to quality infrastructure which is critical for decent standard of life.

Various researchers have stated reasons why projects are abandoned. Irfan, (2019) stated that organizations failed to deliver on their projects due to lack of project management ca-

pabilities/knowledge and absence of project management structures and a well-defined project lifecycle. In a related submission, Hemanta, (2012) averred that inefficient design and lack of effective site management are critical to project abandonment. This was corroborated by Nzewke and Oladejo et al. (2015); they stated that poor project conception/design and planning were major factors.

To bridge this gap, this study has revealed that tailored PCM and the Logical Framework is one of the most common approaches used in project management for both planning, monitoring and evaluation of projects in IDAs and has recorded some modest successes. Also, it serves as a model for organisations to follow and enhance their capacity in project management. Therefore, the need to explore these project management processes (or an adaptation) for interventionist agencies in Nigeria becomes imperative. The overarching purpose of this study is for LIAs in Sub-Saharan Africa (Nigeria in particular) to develop and promote the use of a tailored project management process/framework to combat the myriads of poor project performance including project abandonment in their domain and bring up greater awareness of its use to government and project administrators in the LIAs to mitigate poor project performance including abandonment.

Study Aim and Objective

The aim of this study is to achieve improvement in projects delivery embarked on by interventionist agencies in Nigeria. To achieve this, this research will critically review literatures and identify current trends, understand critical success factors, and causes of project abandonment. Thereafter it will bring up a better project management framework through consensual opinion of experts in a focus group discussion.

What are the research Questions This Study Aims to Answer

Can the study of PMM/project management framework in IDAs be of interest to LIAs in Sub-Saharan Africa?

Efficient Project Monitoring and Evaluation

Indeed, when projects are executed following well laid down methodology and turn out to be successful such projects could be regarded as efficiently executed (Ika et al., 2016). The outcomes of projects executed especially the ones that would impact lives both globally and locally has recently caught the attention of researchers worldwide. In that regard, Golini et al, (2014) suggested that organizations who desire to achieve on their organizational objectives should put in place appropriate measures for project evaluation and monitoring. Ika et al, (2016) and Eze (2014) are of the opinion that extra care in terms of planning, competence of the organisations and PMs' must be evaluated to ensure projects are efficiently delivered.

The Project Management Book of Knowledge (PMBOK, 2021) set standard guidelines which are widely accepted and consistently applied, continually stresses the importance of monitoring and evaluation in achieving project success. A study carried out by Prabhakar (2008) informed that monitoring and evaluation was one of the factors leading to project success. Camilleri (2012) noted that evaluation by IDAs and NGOs showed both accomplishment and also demonstrate accountability to stakeholders, which could enhance their fund drive, whilst enabling the organisations to sustain activities in developing countries. Golini and Landoni, (2014); Hermano et al. (2013); Ika et al. (2012), and Lopez et al. (2014) suggested that monitoring and evaluation techniques could help organizations achieve their overall strategic goals including identifying their strengths and weaknesses in addition to assisting in delivering their projects' derivatives to their stakeholders.

According to Shapiro (2007), monitoring and evaluation involve the systematic gathering

and analysis of data as well as the procedures used to assess the degree to which goals and milestones are met. In the same vein, Papke-Shields et al. (2010) suggested that achieving success on a project could be enhanced when measures are put in place to monitor the progress of the project constantly. According to their study, monitoring and evaluation was relevant in management of project scope, time, cost, quality, human resources, communication, and risks. Quynh et al. (2018) informed that project management tools and techniques provide the efficiency and effectiveness in monitoring and evaluating projects. The authors claimed that appropriate tools and techniques have been discovered and applied widely for a long period of time among project managers around the world with great contributions to the success of projects.

Mladenovic et al. (2013) suggested a two layers approach for the assessment of Private-Public Partnership projects. The first layer was based on evaluation of project objectives from the viewpoint of each stakeholder, profitability for private sector, effectiveness, and value for money for public sector, and level of service for users. This idea was corroborated by Cooke-Davies (2002), who advocated accessing project success into two concepts, project management success and stakeholder’s satisfaction/organization’s achievement of its goal.

Golini et al. (2017); Middleton (2005); and Martinez (2011) asserted that Logical framework (LF) is one of the most common approaches used in project management for both planning and monitoring of projects. It is a tool as conveyed by the different authors that is applicable for governments, ID agencies and NGOs that are engaged in infrastructural development as shown in Figure 1. The advantages of LF include its simplicity, and efficiency in data collection, recording and reporting.

Project Description	Indicators	Sources of Verification	Assumptions
Overall Objective			
Purpose			
Results			
Activities			

Fig 1 Logical Framework by Golini et al. (2017)

Hummel, (2010) noted that whatever the approach used, at least the basic principles for monitoring and evaluation which are measurable objective, performance indicator, target and periodic reporting should be used in a reporting tool and Alotaibi (2011) stated that lack of structures for monitoring and evaluation purposes in any organizations could have a negative effect on the project success. Therefore, deliberate measures should be put in place before during and after the projects to access its impact on the populace. In addition to being able to deliver on the projects, methodologies for evaluation of the projects should also be appraised. This allows the organisations to know their strength, weaknesses and where in future the organisations can improve upon.

Additionally, from the thoughts of Golini et al. (2017); Hummel (2010) and Alotaibi (2011), the study of PMM in IDAs should be of interest to LIAs in so many fronts. Firstly, impactful projects execution either by international donor agencies or local agencies must be well formulated during the planning stage with some specific methodologies/frameworks to guide the project from beginning, during and to the end of the project so that the objective of such project could be said to have been achieved. Therefore, the idea of deploying PCM/LF by ID agencies or adapted project management methodologies by NGOs on their projects is instructive. LIAs in Sub-Saharan Africa could adapt same measures in order to be successful on their projects and minimise incidence of abandonment. Furthermore, any study on project abandonment will need to recognise the full range of stakeholders’ expectations and their respective roles in contributing to that abandonment.

Gleaning from the above, there is a consensus amongst researchers that adoption of any approach in monitoring and evaluation helps in repositioning organisations for better and more importantly their performance in future projects while the lack of it attracts consequences that are detrimental to the corporate image of the organisation(s) including failure to attract funds for its operation.

Efficient Project monitoring and Evaluation in IDAs and NGOs

Ziesemer (2016) noted that developmental aid has become more relevant and instrumental to improving socio-economic conditions of third world countries and other emerging economies. Riddle (2007) and Youker (2003) informed that projects by IDAs and NGOs could vary in sizes and use and range from building infrastructures that enhance development to health, and various agriculture initiatives. As a result, IDAs and NGOs are usually required to conform to strict project reporting process to satisfy a wide spectrum of stakeholders in addition to this being a requirement for access to project financing (Crawford et al, 2003; Hermano et al, 2012 and Lopez et al, 2014). Thus, deliberate measures are put in place by the various IDAs and NGOs to monitor and evaluates projects impacts and the agencies' effectiveness.

Monitoring and evaluation in IDAs and NGOs are integral tools for ensuring the effectiveness of international development performance (Lopez et al, 2014). It is important for the successful management of projects (Nyonje et al, 2012), which is determined by placing emphasis on lean construction, reducing waste to the barest minimum (Rogers and Williams, 2006). Without effective planning, monitoring and evaluation (UNDP, p 5), it will be difficult to ascertain the progress being made on a particular endeavour and also determine how organisation can improve on its effort going forward.

However, Connelly (2004) viewed monitoring and evaluation as a management function; the author contended that its main functions include making information available and processes to be timely and at the right time to enable management to take an informed position on issues. This position was collaborated by the UNDP (2002a, b), which described monitoring and evaluation as a management function of the project manager, thus a reliable management tool that can be used to improve the way governments and organizations achieve their goal on the projects they undertake. Furthermore, for monitoring and evaluation to have focus, efficacy, and for the gains to be properly harnessed to meet the agencies' overall objectives, researchers suggested that it should be structured and sequential. In that sense, (Estrella and Gaventa, 2010) argued that it should begin with data collection (as the starting point) of the expected project. These data are further processed and assessed against the overall objectives of setting up the project (US-AID, 2010).

Armstrong et al. (2013) suggested the next step could be the planning phase. The author averred that the planning phase take cognizance of all assumptions needed for the realization of the projects, including assumptions on adequate budgetary allocation, capacity of the project team, procurement method to be adopted, political consideration, feasibility, timeline, environmental challenges, and ethical consideration. In the view of (Muzinda, 2007), he suggested that the third phase to be the structural framework. The author claims that in order to assess the value and efficacy of IDAs' and NGOs' programmes, it is important to comprehend the motivations behind data collection, analysis, and reporting on the performance of any organisation.

The fourth phase involves deliberate budgetary provision for the monitoring team responsible for conducting monitoring and evaluation procedure on a project (Kelly et al., 2004). The next phase as advocated by (McCoy et al., 2005) is the scheduling phase. It involves a clear programme, timeline and how often data collection should be carried out by the monitoring team. The next is the involvement of all stakeholders. Stakeholders' participation is key especially for agencies to ascertain the suitability of such a project in that geographical region (Muzinda,

2007).

According to the literature there are different tools and other adapted tools that IDAs and NGOs deploy for project monitoring and evaluation. Apart from the Logical Framework, there are other adaptations such as the LFA, a 4 x 4 Matrix (as contained in Figure 2) which is the oldest and widely used tool in IDAs/NGOs for project design, establishing goals/objectives and appraisal including monitoring and evaluation (Crawford et al, 2003; Golini et al, 2016). The LFA gives a detailed summary of why the project should be undertaken, who the project will benefit, the outputs of the projects, what inputs are required to achieve the outputs and the assumptions required to ensure the project is successful (Couillard et al. 2009). However, the LFA had proved to be inadequate (Crawford et al, 2003). The major pitfalls in the LFA include lack of stakeholders’ involvement, difficulty in understanding some of the terms, assumptions not being adequately defined, as well as no definite timeline for the realisation of the project being included (Couillard et al., 2009) thereby giving way to adaptations.

	Summary	Indicators	Means of Verification	Assumptions and Risks
Goal				
Purpose				
Components				
Activities				

Fig. 2. Logical Framework Approach adapted from Golini et al. (2017)

For instance, Couillard et al. (2009) stated that the German Technical Cooperation (GTC) developed the LFA into a more practical, systematic called ZOPP from the German, Zielorientierte Projektplanung or, in English, the GOPP (Goal-Oriented Project Planning) approach. Crawford et al. (2003) considered adding a time dimension to the conventional LFA and proposed a newer concept, the Monitoring and Evaluation Information System (MEIS). Being an adaptation from the LFA, the author emphasized that it was designed to mitigate poor project performance, demonstrate accountability, and promote organisational learning for the benefit of future projects. In this same vein, Hermano et al. (2012) argued that the inefficiency of LFA birthed Project Management for Development Professionals (PMD Pro 1), he further claimed it was developed by Project management for NGOs (PM4NGOs). Couillard et al. (2017) also updated the LFA and proposed a newer version called Logical Framework Approach – Millennium (LAF–M). The author also said that the diverse tools in IDAs/NGOs were designed to enhance project success, improve accountability, and provide lessons learned to organisations for the benefit of future projects. A breakdown of researchers who formulated other adaptations from the LFA are contained in Appendix A.

Extrapolating the divergent thoughts of the researchers’ above on what monitoring and evaluation entails, it can safely be deduced that monitoring and evaluation in IDAs and NGOs is geared towards improving effectiveness, accountability, and efficiency on a project through either the LFA, MEIS, PMD Pro 1, PM4NGOs or LAF – M. In that regard, it is observed that these project management tools in IDAs and NGOs are efficient and effective because they have been improved upon over time, domesticated by the various IDAs/NGOs, and made efficient, thereby enhancing project success. This is instructive for LIAs in Sub-Saharan Africa to note; it is necessary to adapt tools to project manage their construction works in order to ensure success on their project.

Methods and Procedures

To achieve the objective and to understand efficient project monitoring and evaluation through project management tools in IDAs and NGOs, a systematic review of literature was

conducted. Qualitative data analysis was carried out to identify empirical evidence of the application of PMMs/frameworks in project planning, monitoring and evaluation in IDAs and NGOs. A qualitative methodology is deemed appropriate for this study as it will assist in identifying findings from the various literatures on the subject under discourse which could aid in achieving greater understanding and acquiring higher level of conceptual or theoretical development which could be beyond what can be achieved through independent study (Campbell et al., 2018).

Additionally, Nobel et al. (2016) emphasised that Grounded Theory is a method of study with generation of theory which is grounded in data that has been systematically collected and analysed. This study therefore leveraged on Glaser et al. (2017)'s approach to grounded theory, brought up the various nomenclatures discovered from the literature from the researchers' viewpoint. These nomenclatures are contained in Appendix A.

Accordingly, the research stages in this study consist of identification of journals, review of journals, definition of keywords, and classification of journals based on the keywords. To identify suitable literature, inclusion and exclusion criteria were developed for this study which aim to answer the research question. This laid the foundation for the development of reliable inclusion and exclusion criteria as shown in Table 1. Furthermore, Moher et al. (2009) asserted that a systematic review is an appraisal of a clearly prepared question that uses systematic and unequivocal techniques to identify, select, and critically appraise relevant research and to collect and analyse data from studies that are included in the review while Meta-Analysis is the use of statistical techniques in a systematic review to integrate the results of included studies.

Table 1

Systematic Literature Review using inclusion and exclusion criteria (Source: Adapted from Mengist et al., 2020 and Moher et al., 2009)

Serial (a)	Criteria (b)	Decision (c)
1	Journal articles published between 2000 and 2021 were only considered to maintain currency	Inclusion
2	Journals published in a scientific peer-reviewed journal	Inclusion
3	Journals on monitoring and evaluation in IDAs and NGOs	Inclusion
4	Keywords in title (Non-Governmental Organizations, Tools, Project Managers, Local Development Agencies), or abstract section of selected journals	Inclusion
5	Journals written in English language	Inclusion
6	Duplicates, book chapters, non-international journals	Exclusion
7	Journals that were not accessible, review papers	Exclusion
8	Journals which discuss theory, concepts, or proposals without focusing on IDAs/NGOs (on effective project and monitoring evaluation in IDAs/NGOs)	Exclusion

In that sense, existing literature on project management literature, ID literature and also strategic management literature for papers focusing on efficient project monitoring and evaluation and project management methodology tools was used for the study which also incorporated the Preferred Reporting Items for Systematic review and Meta-analysis (PRISMA) as contained in Figure 3. Subsequently, the aforementioned literatures were found using scientific recognised academic search engine on three prominent databases, ScienceDirect, Scopus, and Springer. Figure 3 explains the four stages of the literature selection process. The search criteria used to identify the literature within the scope of this study were "Project monitoring and evaluation and project management framework and international development agencies and Non-Governmental Organisations". Afterwards, the search was further refined by considering only those papers focusing on efficient project monitoring and evaluation in IDAs and NGOs. From the research, a

list of 10 papers on project monitoring and evaluation specific to IDAs/NGOs was obtained.

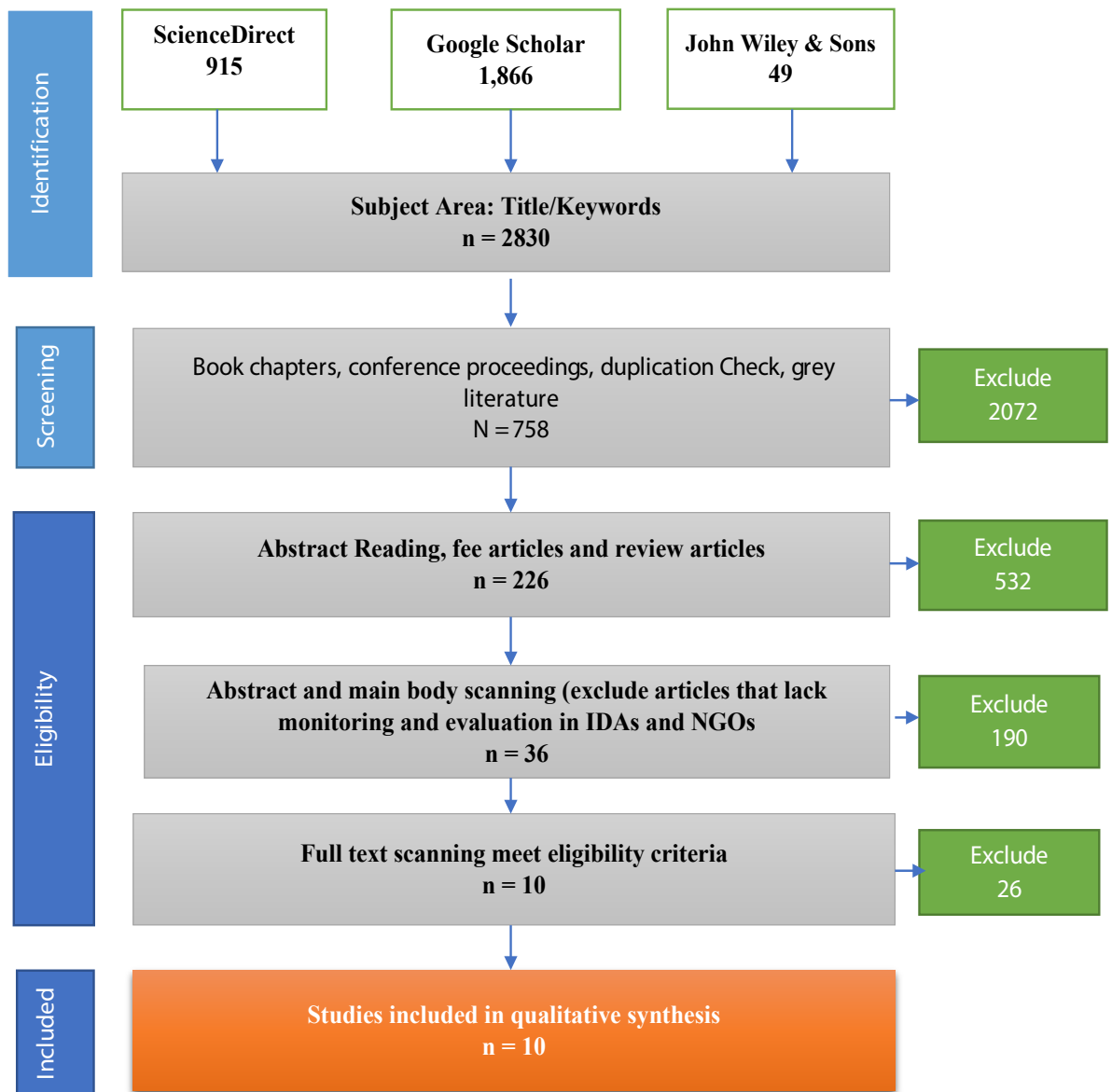


Figure 3: The flow chart for the Literature Selection Process (Source: Adapted from Mengist et al.,2020 and Moher et al., 2009)

Results and Discussion

As previously stated, the criteria used in developing the classification of the various adaptations of the LFA are contained in Table 2.

Table 2

Criteria used to classify the various adaptations of the LFA from the chosen articles (Source: An adaptation from Mengist et al., 2019)

Serial	Criteria	Categories considered	Justification
(a)	(b)	(c)	(d)
1	Year of Publication	Between 2000 - 2020	To maintain currency

2	Utilisation area	IDAs and NGOs	Lessons learnt would be valid for LIAs
3	Name of Journal	Literatures from Scientific databases on project management literature, ID literature (relating to project monitoring and evaluation in IDAs and NGOs)	Knowledge gathered would be valid
4	Project Monitoring and Evaluation	Specifically, in IDAs and NGOs	Useful for LIAs to draw from
5	Type of Data	Secondary Data, derived from peer reviewed journals only	Current knowledge on Project monitoring and evaluation would be valid

Project Management Methodologies in International Development Agencies

Golini, Corti and Landoni (2017), described PMMs in relation to ID agencies as specific methodologies developed and suited to ID agencies. The objective of these specific PMMs is to monitor the project from conception to the end as well as assess its social impact on the people and the environment (Newcomer et al., 2013). From Golini, Corti and Landoni (2017, p 128) scholarly work conducted between 2008 – 2009 on PMs that were interviewed, it revealed that over 90 per cent of PMs had adopted either the LF or PCM on a project while working on ID projects. It revealed PCM was adopted in 74 per cent of the total projects managed, and the LF in 81 per cent of the projects.

This implies the use of PMMs had gained a wide acceptance amongst PMs working on ID projects. Although the survey also revealed that some PMs working in some Non-Governmental Organizations (NGOs), posited that PCM and LF were not adopted on all the projects (Golini et al, 2017), by implication PCM and LF were used for specific project while other PMs adapt and adopted own methodology. However, the common goal for these varied approaches is to achieve sustainable and project success that insures environmental, political, social, and economic wellbeing of the society irrespective of cultural and ethnic diversities and the geography that uniquely defines mankind (Bell and Morse 2005; Baldock et al., 2001).

Stewart (2004) emphasized that the purpose of PMM to an organization is to provide a model approach that can be used to deliver a project, to promote the use of best practices that will increase a project's probability of success. Therefore, some of the key components of PMM (Charvat 2003, Stewart 2004 and Crawford, 2002) suggested that the framework be comprised of phases, activities, and tasks; guidelines that define the activities required to generate deliverables; methods that provide how to perform activities. To this end, Landoni et al. (2011) stated that Baum introduced the project cycle concept into ID projects known as Baum project cycle.

According to Landoni et al. (2011, pp. 45 – 61) Baum (1970) introduced a specific approach for ID projects. He organised the activities into a cycle (project cycle) which have been widely adopted because it is well structured and allows people to work together while reigning in the project objectives of the organization as shown in figure 4.

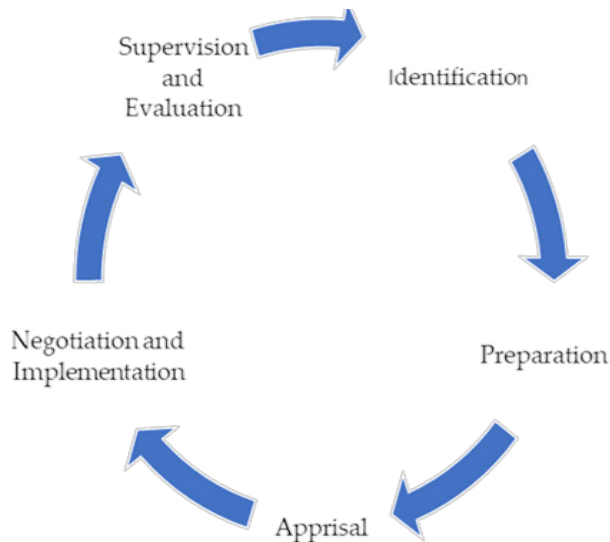


Fig 4: Baum's Project Cycle (Baum, 1970).

The authors also averred that most ID agencies had adapted the project cycle to fit into their respective agencies. The goal is to learn the basic lessons of good project management and to apply them to achieve results. Also, Biggs and Smith (2003) corroborated Landoni et al. (2017) asserting that PCM is a framework rather than a tool in itself, consequently different tools have been developed within the PCM.

For instance, United States Agency for International Development (USAID) mostly deploys the Performance Management Plan (PMP) and Results Framework (RF) to administer its projects (Landoni et al, 2011). Landoni et al. (2011) examined the various PM standards adopted by five of the main worldwide ID agencies and their tools and techniques are attached as Table 3 while each of the agencies' derived tools/techniques are contained in Table 4. The five main agencies include:

- Australian Agency for International Development (AUSID)
- Canadian International Development Agency (CIDA)
- European Commission (EC)
- Japan International Cooperation Agency (JICA)
- United States Agency for International Development (USAID)

Table 3

Different Types of Project Management Tools/Techniques in Use By 5 Main ID Agencies in The World (Source: Landoni et al., (2011))

Serial	Name of Agencies	PCM	LF	LM	PMF	RR	PDM	RF	PMP	GNATT CHART	WBS	AC	RS
(a)	(b)	(c)	(d)	(e)	(f)	(g)	(h)	(j)	(k)	(l)	(m)	(n)	(o)
1	AUSID												
2	CIDA												
3	EC												
4	JICA												
5	USAIDS												

LEGEND

PCM = Project Cycle Management
 LF = Logical Framework
 LM = Logical Model
 PMF = Performance Management Framework
 RR = Risk Register
 PDM = Project Design Matrix
 RF = Results Framework
 PMP = Performance Management Plan
 WBS = Work Breakdown Structure
 AC = Activity Cost
 RS = Resource Schedule

Table 4

Derived Tools/Techniques in use by some Main ID Agencies in the World (Source: Landoni et al., (2011))

Serial	Some Main ID Agencies	Derived Tools/Techniques
(a)	(b)	(c)
1	CIDA	LM, PMF, RR
2	EC	Gnatt Chart, WBS, AC, RS
3	JICA	PDM
4	USAID	RF, PMP
5	AUSID	NIL

LEGEND

PCM = Project Cycle Management
 LF = Logical Framework
 LM = Logical Model
 PMF = Performance Management Framework
 RR = Risk Register
 PDM = Project Design Matrix
 RF = Results Framework
 PMP = Performance Management Plan
 WBS = Work Breakdown Structure
 AC = Activity Cost
 RS = Resource Schedule

From the various submissions by Golini, Corti and Landoni (2017), Landoni et al (2011), and Stewart (2004), the researchers agreed that the purpose of PMM to organisation is to serve as model to deliver on an agencies' goals, promote the use of best practices that will ensure project success hence the adaptation of Baum project cycle by IDAs and NGOs, respectively.

Can the Lesson on the diverse use Of PMMs in IDAs/NGOs drawn from the Literature assist in Institutionalising a better Project Management Framework in LIAs?

From the study, the work of Landoni et al. (2011) had revealed that IDAs and NGOs had diverse PMMs in their domain derived from Baum's Project cycle. Other varieties of frameworks amongst the IDAs were geared to achieve the same purpose. This was upheld by Diallo and Thuillier (2013), who said that the varieties offered a framework with an efficient system that allows groups of persons to work together towards achieving a set objective. The diverse tools were for project governance and stakeholders' assessment which had proven to be successful when deployed by knowledgeable PMs (Landoni et al, 2011). Its adoption and deployment in IDAs/NGOs are directly proportional to how knowledgeable the PMs in the IDAs/NGOs are Landoni et al. (2011). Thus, the authors suggested that for PMs to be versatile in the use of their various PMMs, such PMs could be trained on how to use the frameworks for optimal performance. Therefore, in order to curb this gap, Ozmen (2013) suggested that organisation should adopt a PMM peculiar to them; failure to do so could lead to unpleasant consequences.

Accordingly, from the thoughts of these researchers above on the diverse use of PMMs, it could serve as a lesson to the LIAs to learn from. Furthermore, considering that IDAs and NGOs do not have a common PMM but had adapted one for use in their various organisations, LIAs in sub-Saharan Africa could also adapt a tailored PMM that could serve as a framework, trained their various project administrators to become proficient in the use of the adapted PMM for their project governance and assessment.

Can the study on efficient Project Management Frameworks in IDAs Assist LIAs mitigate poor project performance including abandonment?

From the foregoing analysis, this paper has clearly revealed the use of adapted frameworks by PMs to monitor projects to completion, it also incorporates the fact that some PMs working with some NGOs had to adopt a project management framework to suit their project in order to achieve its set objective. Therefore, any organization that wants to remain relevant in delivering on its set objectives, could embrace an appropriate framework that could bring about the desired change (Ozmen, 2013). Furthermore, having an integrated PM framework will further enhance an organisation's capacity in project management. Consequently, PM framework will play a dual purpose, having common language, and processes respectively which are fundamentals of project management, and seek to act as a reference point in addition to serving as feedback mechanism to the organisation (The Standish Group, 2010; Wysocki, 2006).

Plewinski (2014), therefore suggested that in order for an organisation to select an efficient PMM, the methodology must fulfil certain criteria which could be appraised on four dimensions. These include: Can the methodology be applied to different project types? Does it support the development of detailed work plans, cost, and resource control and other PMBOK elements, for a particular project? Is the chosen methodology understandable and easy to use? Does the use of the methodology contribute to better (more timely, cost effective, and/or higher quality) results on projects? Therefore, it is imperative to deduce from both Ozmen (2013) and Plewinski (2014) works that having fitted PMM in an organisation that is well deployed could assist in planning and will assist organisations efficiently to achieve success in their projects.

Conclusion

ID agencies executing projects in developing nations have recorded some modest achieve-

ments over the years by deploying specific PMMs by PMs in the execution of projects despite the difficult terrain, political instability, corruption, and political interference. The PMs' leveraging on their knowledge of how to use the tools to plan and monitor ID projects have achieved some successes. The study revealed that various PMs had used either PCM or LF or a combination of both in monitoring projects from inception to completion. Some PMs working in some NGOs had also adapted and adopted other suitable PMMs or frameworks fitted to their organisations to plan and monitor progress of work. Thus, it is safe to deduce that having a well fitted PMM or framework can assist agencies or organizations to achieve project success. Accordingly, LIAs in Sub-Saharan Africa could therefore adopt a tailored PMM or framework in line with the overall objectives of the organization to enhance its capacity in project administration.

Recommendations

It is recommended that:

1. LIAs adapts and adopt a tailored PMM on its project to minimise the incidences of corruption and poor project performance including abandonment.
2. LIAs to train PMs to become knowledgeable on the adopted PMM or framework to achieve success on its projects.

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Biography

Eric is interested in the application of project management methodology concepts to planning, monitoring/evaluating, and tracking construction projects to reduce waste, increase stakeholders' satisfaction and minimise incidences of poor project performance. Eric is currently doing a PhD at the University of the West of England (UWE) Bristol United Kingdom, investigating Local Interventionist Agencies (LIAs) in sub – Saharan Africa plagued with poor project delivery using the NDDC as a Case Study. Eric received his initial education in Architecture at the then Edo State University, Ekpoma before achieving an MSc in Architecture at the Ambrose Alli University, Ekpoma -Nigeria.

References

- Australian Agency for International Development (2003) The Logical framework approach. Canberra, Australia: AusAID.
- Ayodele, E.O. & Alabi, O.M. (2011) Abandonment of construction projects in Nigeria: causes and effects. *Journal of emerging trends in Economics and management sciences*. Vol 2, (2), pp. 142-145.
- Bell, S. & Morse, S., (2005). Delivering sustainability therapy in sustainable Development Projects. *Journal of Environmental Management*. 75 (1), pp. 37 – 51. 3.
- Campbell, K., Massey, D., Broadbent, M., & Clarke, K. (2018). Factors influencing clinical decision making used by mental health nurses to provide provisional diagnosis: A scoping review. *International Journal of Mental Health Nursing*.
- Crawford, J.K., The Project Management Maturity Model. 3rd ed. CRC Press: Auerbach Publishers 2006.
- Charmaz, K. (2006). Constructing Grounded Theory: A Practical Guide through Qualitative Analysis. Lon-

don: Sage Publications.

- Charvat, J. (2003). *The Project management methodologies: Selecting, implementing, and supporting methodologies and processes for projects*. Hoboken, NJ: *John Wiley and Sons Inc*.
- Cooke-Davies, T. (2002) The real success factors on projects. *International Journal of Project Management*. [online]. 20(3), pp. 185-190. [Accessed 6 December 2001].
- Couillard, J., Garon, S., & Riznic, J. (2009) The Logical framework Approach – Millennium. *The Project Management Journal*. [online]. 40(4), pp. 31 - 44. [Accessed on 1 December 2009].
- Diallo, A. & Thuillier, D. (2004). The success of international development projects: The perceptions of African project coordinators. *International journal of project management*. 22(1), pp. 19 – 31.
- Eze, O.M. (2014). The causes of abandoned projects: Niger Delta Development Commission (NDDC) hostel project in Nigerian universities, *Journal of African Studies and Development*. 6(5), pp. 87 – 91.
- Estrella, M. & Gaventa, J. (2010) Who counts reality? Participatory monitoring and evaluation: a literature review IDS Working paper (70), *Institute of Development Studies, Brighton*. Available at: <https://opendocs.ids.ac.uk/opendocs/handle/20.500.12413/3388>.
- European Commission (2016) *Project Management Methodology Guide Open Edition*[online] EU Bookshop (2016). Available from: <http://bookshop.europa.eu> [Accessed 29 November 2016].
- Glaser, B.G. & Strauss, A.L. (2017) *Discovery of Grounded Theory: Strategies for Qualitative Research* [online]. Routledge. [Accessed 07 June 2019].
- Golini, R., Corti, B. & Landoni, P. (2017). More efficient project execution and evaluation with logical framework and project cycle management: evidence from international development projects. Impact Assessment and Project Appraisal. *International journal of Project management*. 37(2), pp. 128 – 138.
- Gupta, S.K., Gunasekaran, A., Anthony, J., Gupta, S., Bag, S., & Rouband, D. (2019). Systematic literature review of project failures: Current trends and scope for future research. *Computers and Industrial Engineering Journal*. 12 pp. 274-285. 14.
- Hermano, V., Lopez-Paredes, A., Martin-Cruz, N. & Pajares, J. (2013) How to manage international development projects successfully. Is the PMD Pro1Guide going the right direction? *International Journal of Project Management*. [online]. 31(1), pp. 22-30. Available at: <https://doi.org/10.1016/j.ijproman.2012.07.004>.
- Hemanta, D. (2012) Cost overruns and failure in Project Management: Understanding the roles of key stakeholders in construction projects in Australia. *Journal of construction Engineering and Management* Vol.139, (3),pp. 1-2.
- Ika, L. A. (2012) Project management for development in Africa: Why projects are failing and what can be done about it. *Project Management Journal*. [online]. 43(4), pp. 27-41. [Accessed on 1 August 2012].
- Ika, L.A., Diallo, A. & Thuillier, D. (2009) Project Management in the International Development Industry. *International Journal of Managing Projects in Business*. [online]. 3(1), pp. 61-93. [Accessed on 11 May 2009].
- Ika, L. A., Diallo, A. & Thuillier, D. (2012) Critical success factors for World Bank projects: An empirical investigation. *International Journal of Project Management*. [online]. 30(1), pp. 105 – 116. Available at: <https://doi.org/10.1016/j.ijproman.2011.03.005>.
- Ingwe, R., & Mbotto, W. (2012). Project abandonment, Corruption and Recovery of unspent Budgeted Public Funds in Nigeria. *Romanian Journal of Economics, Institute of National Economy*. 34(1), pp. 24 – 26.
- Irfan, M. (2019). The effect of Project Management Capabilities on Project Success in Pakistan. *Journal of the Institute of Electrical and Electronics Engineers*. 7(1).

- Isidiho, A.O. & Mohammad, S.B.S. (2015). The role of people's participation, monitoring and evaluation in the successful implementation of Niger Delta Development Commission (NDDC) projects in selected communities in Imo State. *Scottish Journal of Arts, Social Sciences and Scientific Studies*. 24(11), pp. 125-128.
- Jacobs, A., Barnette, C., & Panford, R. (2010) Three approaches to monitoring: Feedback systems, Participatory, Monitoring and Evaluation and Logical frameworks. *Institute of Development Studies*. [online]. 41(6), pp. 36-44. [Accessed on 6 November 2010].
- Kessi, E., Agyekum, K., Baiden, B.K., Tannor, R.A., Asamoah, G.E & Andam, E.T. (2018) Impact of Project Monitoring and Evaluation Practices on construction Project success criteria in Ghana. *Built Environment Project, and Asset Management*. [online]. pp. 2-25. [Accessed 15 March 2019].
- Khany, D. B. & Moe, T. L. (2008). Success criteria and factors for international development projects: A life-cycle-based framework. *International Project Management Journal*. 39(1), pp. 72 – 84.
- Landoni, P. & Benedetta, C. (2011). The Management of International development Projects: Moving toward a standard approach or differentiation? *Project Management Journal* [online]. 42(3), pp.45 – 61.
- Mengist, W., Soromessa, T., & Gudina, L. (2020). Method for conducting systematic literature review and Meta-Analysis for environmental science research. *Science of total Environment Journal*. 702(7), pp. 1-11.
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G., & The Prisma Group (2009) Preferred Reporting Items for Systematic Reviews and Meta-Analysis: The Prisma Statement. *Annals of Internal Medicine* [online]. 151(4), pp. 264-269. [Accessed 22 June 2019].
- Nobel, H. & Mitchell, G. (2016). What is grounded theory? *Evidence-based Nursing journal*. Vol 19 (2), pp 2-5. Available from: Doi:10.1136feb-2016-102306
- Ozmen, E. (2013). Project management methodology (PMM): How can PMM serve organizations today"? Paper presented at PMI® Global Congress 2013—EMEA, Istanbul, Turkey. Newtown Square, PA: Project Management Institute.
- Papke-Shields, K.E., Beise, C. & Quan, J. (2010) Do Project Managers practice what they preach, and does it matter to project success? *International Journal of Project Management*. [online]. 28 (7), pp. 650-662. [Accessed on 6 December 2009].
- Plewinski, P. (2014). Design and implementation of a project management methodology: From ad hoc project environment to fully operative PMO in three years. Paper presented at PMI® Global Congress 2014—North America, Phoenix, AZ. Newtown Square, PA: Project Management Institute.
- Stewart, J. The meaning of strategy in the public sector: *Australian Journal of Public Administration*. 63(4), pp.16-21, 2004.
- UNDP (2002a) Linking poverty reduction and environmental management: policy challenges and opportunities, The World Bank, Washington, DC.
- UNDP (2002b) Handbook on Monitoring and Evaluating for Results, Evaluation Office, United Nations Development Programme [Accessed August 8, 2018].
- United States Agency for International Development (USAID) (2010) Map of earthquake affected areas and population movement in Haiti. Available at: www.usaid.gov/ourwork/humanitarian_assistance/disaster_assistance/countries/haiti/template/ay2011/haiti_10222010.pdf [Accessed October 25, 2010].
- Ziesemer, T. (2016) The Impact of Development Aid on education and health: Survey and the new evidence for low-income countries from dynamic models. *Journal of international Development*. [online]. 28(8), pp. 1358-1380. Available at: <https://doi-org.ezproxy.uwe.ac.uk/10.1002/jid.3223>.

APPENDIX A

The criteria used for the extraction of information from the selected articles (Source: An adaptation from Mengist et al., 2019)

Srl	Authors	Year	Citation	Name of Journal	Abstract/Keyword	Secondary Data Collection	Study Area	Justification
(a)	(b)	(c)	(d)	(e)	(f)	(g)	(h)	(i)
1	Crawford et al., (2003)	2003	336	ScienceDirect	Meet the objective of the study	Peer Review	IDAs/NGOs	Proposed 3D- log frame adapted from the LFA to be more effective and efficient
2	Couillard et al., (2009)	2009	95	Wiley online library	Meet the objective of the study	Peer Review	IDAs/NGOs	Proposed LFA-M adapted to be more effective and efficient
3	Golini et al., (2017)	2017	25	Google Scholar	Meet the objective of the study	Peer Review	IDAs/NGOs	Appropriate Adapted LF recommended
4	Golini et al., (2014)	2014	26	Google Scholar	Meet the objective of the study	Peer Review	IDAs/NGOs	Right mix of PMM tools with PM4NGOs for an enhanced project derivative
5	Golini et al., (2017)	2017	9	Google Scholar	Meet the objective of the study	Peer Review	IDAs/NGOs	Advocated the use of LF in NGOs for projects monitoring and reporting
6	Landoni et al., (2011)	2011	85	Wiley online library	Meet the objective of the study	Peer Review	IDAs/NGOs	The history of PCM and LF was stated and various adaptations by NGOs
7	Hermano et al., (2013)	2013	60	ScienceDirect	Meet the objective of the study	Peer Review	IDAs/NGOs	Proposed PMD Pro1 for PM in IDAs/NGOs
8	Jacobs et al., (2010)	2010	2	Wiley online library	Meet the objective of the study	Peer Review	IDAs/NGOs	Comparison of three approaches and their usefulness in enhancing project management in NGOs
9	Ika et al., (2009)	2009	144	ScienceDirect	Meet the objective of the study	Peer Review	IDAs/NGOs	Appropriate use of project monitoring and evaluation tools enhance success in IDA/NGO projects
10	Matos et al., (2019)	2019	7	ScienceDirect	Meet the objective of the study			High use of project management tools in IDAs/NGOs hinged on the willingness of project administrators to adopt it use for better performance

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SHORT ESSAY

Gaining Confidence Through Collaboration

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In the summer of 2022, the SWDTP ran its first ever summer school. Summer schools are programmes that involve a series of talks and activities on a particular topic that are run by universities or private organisations (Allcoat, 2016). I was fortunate enough to attend the SWDTP summer school in Bath, which focused on collaboration, employment and wellbeing. This summer school was integral to a personal goal of mine — building my confidence. In this reflection, I will discuss my experience. I hope that through sharing, I will be able to motivate other PGRs to engage in collaborative programmes like summer schools.

Before attending the summer school I had mixed feelings towards collaboration. I understood the benefits of networking and knowing how to work with a range of different people who each have their own views and experiences. However, I had had several negative experiences with collaborative projects. I often found that I was carrying the project forward and taking on the bulk of the workload, which made these experiences stressful and tiring. I did realise that a part of the problem laid within me as I struggled to delegate tasks and as I am a perfectionist, I sometimes felt the need to micromanage the project. I was also very shy and speaking up about things that felt unjust was difficult for me. I knew I wanted to address my attitude towards collaboration and improve my confidence. I did not expect I would achieve both of these things simultaneously.

One of the main reasons I applied to the SWDTP summer school was to develop my collaboration skills. From connecting with members of other disciplines, we can learn about a number of other ways to approach our research and we can benefit from the different perspectives they have to offer. In today's world, where face-to-face networking has been difficult, the opportunity to connect with people from other disciplines is something that had been missing from my PhD experience. I saw the summer school as a fantastic opportunity to fill this gap and develop invaluable networking skills, whilst learning about topics I am interested in.

The summer school was so much more than I expected and truly allowed me to enhance those skills. The summer school had three key themes, one of which was collaboration. This entailed making new connections with the other attendees that came from different disciplines and universities, and learning how to collaborate effectively. The main group project for the summer

school involved a mock research funding application. We were allocated to small groups of five and set the task of coming up with an idea for a research project that combined our skills and interests. At first, this seemed particularly daunting as we came from very different backgrounds and a common theme was not obvious.

Throughout the summer school, we were guided on how best to collaborate effectively to be able to come up with an idea. One of the key activities we did was a timer task where we each had to talk for three minutes about an assigned topic with no interruptions from our other group members. This was great for encouraging those that often take over the conversation to learn about the importance of listening, but also for those that are often quiet to have the opportunity to speak. As somebody who was often quiet in group settings, I thought this would be impossible for me. I feared that the timer would still be running and I would be completely blank on what to say. However, much to my surprise the timer ran out and I still had so much left to say.

This made me realise that I do have a lot to say and that I often stop myself from speaking up out of fear. So many times, I have had good ideas but felt too shy to speak up in group meetings. Then, someone else would say my idea and be praised for it and I would kick myself for not having said it before. I reflected upon this throughout the week and decided to set myself the challenge of speaking up more. During the week, I made sure I raised my views and concerns to my group members and I pushed myself to present at the end of the week to further improve my confidence. I have since spoken up numerous times in other settings and I feel really good about myself as a result. For example, previously I was uncomfortable with reaching out to more senior academics, but since I have had the confidence to reach out to a lecturer and in turn been given the opportunity to co-supervise a master's dissertation.

I also wanted to address my micromanagement issues, as this was a quality I did not like in myself and I wanted to get better at delegating. I really pushed myself to ensure the work was split up fairly. This worked out extremely well and the final idea was a shared project that I felt proud to be a part of. Unlike with other collaborative projects I had done in the past, I did not feel burnt out, as this time I had not done the majority of the work. This was a very rewarding feeling and I now feel more comfortable with delegating tasks.

Aside from the importance of speaking up and delegating, I also learnt about the importance of taking time to enhance your wellbeing. Group work can be taxing and there are times where you may feel overwhelmed, as if you are not being listened to, or that your social battery is running low. In these situations, it is important to take the time to step away and focus on yourself. The summer school taught us about the importance of self-reflection and taking a step back. We went on independent reflective walks where we were told to think about one key challenge we had. I found this task so useful as it allowed me to just have the time and space for myself, to process the large amounts of socialising we had done and to think through the group project. In future, I will make use of self-reflective walks when things become a little too much, as it enables you to come back to the challenge with a clear and fresh perspective.

Not only was the self-reflective walk great for my wellbeing but also having the opportunity to get away from the stressors of PhD life in a completely new environment really helped me switch off. We were so lucky that the SWDTP paid for our accommodation in a lovely hotel in Bath and all of our food throughout the programme. The hotel rooms were spacious and had a bath, which as PhD students living on a budget is a luxury we often aren't able to have. It was very nice to be able to take that time to relax without worrying about the cost. The summer school also followed a schedule that gave us time off in the evenings to relax. I used to struggle with making the time to relax and would often work into the evenings. This regularly affected my sleep and just before the summer school, I completely burnt out and had to take time out because I became ill. Having a proper schedule and evenings to relax made me feel so much better. I am working on keeping this up now that I have returned to PhD life as I now recognise that if I do not

take the time to relax, my body will make me have to stop.

Another key thing I learnt from the summer school was the importance of looking beyond our disciplines. We are often in shared offices with other people from our discipline and there are few opportunities to interact with those from other fields. I thought that my most influential conversations would be with people from within psychology and more specifically my research group in social psychology. However, the summer school challenged this belief. Although someone in my group was also a social psychologist, our research was very different and someone from another discipline's work was far more connected to mine. I hope that in future I will have more opportunities for interdisciplinary work to discover more connections that are not obvious at first glance. This realisation has inspired me to apply to a series of interdisciplinary workshops that otherwise I probably would not have, as I previously did not fully appreciate the benefits for my research.

Although the week really shaped me as an individual, I also want to focus on some suggestions for improvement. The summer school was female dominated and greater representation of men and non-binary people would have been welcomed. I understand this was due to not many men applying for the programme. However, this is not reflective of the percentage of men studying social science PhDs in the UK, which has a relatively balanced gender split (Vitae, 2022). Therefore, it would be great if summer schools could encourage more men and non-binary people to apply. Presenting students with role models that have attended the course and are like them in terms of their demographics results in more applications to that course (Porter & Serra, 2020). So, perhaps, this could be achieved by sharing testimonials from a range of voices to ensure summer schools are as diverse as possible.

The summer school was undoubtedly a great experience for self-development, collaboration and confidence building. I learnt so much and know it has and will continue to shape my career and personal life. However, I am a little unsure on how best to discuss this experience in job applications, my CV, and interviews. There was a lot of content and putting that across to someone outside of academia is especially challenging for me. I think courses of this nature would benefit from a short session on making the most of them for employability purposes. For example, a template on how to describe a summer school on your CV. This would be my second recommendation for the summer school.

To conclude, writing this reflection has given me the opportunity to think about and voice my thoughts on an important week in my PhD journey. I really hope that through sharing my personal experience of the SWDTP summer school, I have inspired other students to engage in collaborative activities. As PGRs we have a lot of knowledge and many invaluable skills to bring to conversations and I encourage you to challenge yourself and push yourself out of your comfort zone. Whether that is applying to a summer school, or something completely different, push yourself. I promise you will not regret it. I also hope the SWDTP and other higher education institutions or private organisations providing similar programmes will consider my recommendations on how to ensure their programmes are diverse and truly beneficial for PhD students' employability.

Acknowledgements

With special thanks to the SWDTP for accepting me onto their summer school where I learnt so much and had an enjoyable experience that I will never forget. I would like to give an extra special mention to Kate for being the most incredible facilitator I have ever worked with, she made the week amazing and did a wonderful job at bringing us out of our comfort zones.

Biography

Nicole is interested in the ways organisational practices can increase workplace diversity. She has focused on the ways organisations frame their diversity policies and how these framings are perceived by ethnic minorities and their relationship with real-world diversity outcomes.

References

- Allcoat, D. (2016). *Postgraduate Recommendation: Summer Schools*. PhDLife Blog. <https://phdlife.warwick.ac.uk/2016/11/30/postgraduate-recommendation-summer-schools/>.
- Porter, C., & Serra, D. (2020). Gender differences in the choice of major: The importance of female role models. *American Economic Journal: Applied Economics*, 12(3), 226-54.
- Vitae. (2022). *Who does doctoral research in the UK? — Vitae Website*. Vitae.ac.uk. <https://www.vitae.ac.uk/doing-research/are-you-thinking-of-doing-a-phd/who-does-doctoral-research-in-the-uk>.

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SHORT ESSAY

Phd Support Groups: From Sceptic to True Believer

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Abstract

PhDs can be lonely and challenging endeavours; students come across setbacks, imposter syndrome sets in, motivation wanes and productivity slows (Denman et al, 2018 : Gin et al, 2021). However, when students can access quality support, these issues can be overcome (Naylor et al, 2018 : Elliot, 2020). Nonetheless, there can be challenges in being able to access this and pitfalls leading to negative experiences. In order to explore this, this essay will reflect on my own experiences of one type of support: informal PhD support groups. I joined my support group when I started to struggle with my PhD in 2021 despite my scepticism of the benefits and time 'cost'. However, it has offered me the benefits of advice, reassurance, community and collaboration by the way in which it is run and how the members approach it. Thus, I have been converted from sceptic to true believer and I will conclude this essay by encouraging all fellow PhD students to give them a chance.

Keywords: PhD support groups, advice, reassurance, community, collaboration

Introduction

PhD students are commonly studying off-site due to the rise in distance learning, virtual platforms and studying whilst in industry (De Zwart & Richards, 2014 : Naylor et al, 2019). This isolation can help with focus, however, this can unravel when challenges are met and students working off-site can find themselves with a lack of support or community to access (De Zwart & Richards, 2014). However, this sense of isolation is not just limited to those working off-site; students attending a busy campus can still feel alone, unable to access support or worried about asking for help (Cantor, 2020).

When I embarked on my PhD in 2019, I chose to be a part-time distance learner with autonomy being the driver for this choice. However, that began to crumble when I struggled to recruit participants for my research. I immediately started to question if I was capable of doing a PhD. Feelings of inadequacy and imposter syndrome are commonly felt in the postgraduate

community (Lewinski et al, 2017). Students can feel like they are not good enough to do a PhD (inadequate) or that they are academic frauds who are there by luck alone, fear failure and compare themselves unrealistically to others (imposter syndrome) (Craddock et al., 2011). Students need a support network around them to help them overcome these challenges (Bettison & Haven Tang, 2021).

When I experienced recruitment challenges and exhausted all of the strategies I could find (and my supervisors suggested), I summoned the courage to be vulnerable and ask my colleagues for help. I work in higher education, so my colleagues have research experience and many have been or are PhD students. The PhD world can be a competitive one where it can feel difficult to admit that you do not know something or have 'failed' (Wilkinson, 2020). However, my email was met with support; there was no judgement as I had feared, and it became clear that all of them had also experienced difficulties. This communication was advice from individuals which was useful but from that, I was invited to a PhD support group and unbeknown to me the benefits of this group would be the best thing to come out of that email.

One of my colleagues had set the PhD/professional doctorate support group up in 2020 when they were undertaking their own studies, as they realised there were lots of colleagues studying in isolation. Attendees needed to be colleagues but could be studying at any institution/university and located anywhere in the UK (all sessions are online). I knew this group existed before my email, but I had never been as I thought I was too busy and I was not sure what the benefit would be to me or what I could offer to others. It appears time commitments and uncertainty are common fears in accessing groups (Cantor, 2020).

In the past, I had found groups frustrating, with it being quicker to work alone. Nonetheless, the offer to put my problem on the agenda coupled with my desperation meant I decided to try it and I am glad I did. That first meeting was full of solutions (using Twitter, speaking at groups), signposting (researchers in the field), and reassurance. This was helpful in quietening my doubts and being able to recruit participants as well as offering a general sense that I was not a 'failure'. I now attend this group once a month and it has led to monthly writing groups and online networking. Previously that would have sounded like too much of a time commitment but to me the rewards outweigh the costs and actually save me time. However, I must be balanced here as I appreciate that my experience will not be the same for everyone. There can be pitfalls and issues such as group dynamics (Cantor, 2020) but if all the factors line up, they can be a lifeline (Elliot et al, 2020).

What does the literature say?

PhD students can feel a sense of isolation as often they study by themselves. This coupled with the pressure to succeed, feelings of academic fraudulence and the stress of managing studies, means that there can be low wellbeing, and decisions to drop out (Gin et al, 2021 : Van Rooij et al, 2021). However, it has been suggested that support can help overcome these barriers (Naylor et al, 2018 : Elliot, 2020). This comes in many different forms such as support from supervisors, mentoring schemes, social media, friends/family, peers, support groups and writing groups. Studies have suggested that there is benefit in all these support options but there is no agreement on which is best. Nonetheless, it is important to note that there can be barriers to accessing support. These can be practical such as time commitments and availability (Elliot et al, 2020) or less visible such as fears of appearing weak in front of others (Cantor, 2020). Cultural and social views of seeking support can also be a factor with some departments, institutions/universities and countries viewing the need for support differently (Allen, 2019).

Nevertheless, it is agreed that support is helpful and many studies recommend that students try to access support and that institutions/universities do more to encourage it (Wegener et al, 2016). Support can offer advice, increase wellbeing, give a sense of belonging, and increase motivation and productivity (Naylor, et al. 2018 : Elliot, 2020). However, the literature spans the different types of support with few focused solely on informal PhD support groups. Therefore, this essay offers personal reflections on the benefits of PhD support groups whilst drawing on the wider benefits of support outlined by the literature.

What have I learnt about support groups?

When I started to reflect on what benefits I felt and why, I could see that they fit into four themes: advice, reassurance, community, collaboration. These themes are also reflected in the

literature on PhD support.

But before I explore this in more depth it would be prudent to define what a support group is. Support groups are where people meet with the aim of offering support. Some are formal with experts, representatives from institutions/universities or mentors. These can be helpful in advising students, signposting and bringing people together (Page et al 2019). They are often run by an 'expert' and have a specific scheme to work against which can make them restrictive and inflexible (Page et al, 2019). Informal support groups are a collection of peers and have a more flexible agenda. There is not an 'expert' or official institution/university representative although there can be a chair. This type helps students to connect, share problems/successes, advise each other and reduce feelings of isolation (Denman et al, 2018). The type of group I am discussing is the informal type.

Advice

A benefit of groups is that members offer advice and share skills and knowledge (Chatterjee-Padmanabhan & Nielsen, 2018). This has allowed me to reduce the amount of time spent worrying, finding resources or working out how to do something. This social and cultural capital may seem like an obvious benefit but what I think is more interesting to reflect on is how that advice can be given by everyone and that it can be both encouraging and challenging, and that that is a good thing.

My group is based in the UK and made up of members who are at all stages of the PhD/professional doctorate process. We are also from a diverse range of disciplines (education, social science, humanities, medicine, business) and backgrounds (educators, nurses, social workers, managers, administrators) although we are mainly qualitative researchers. Not everyone attends each session but there are often between six and ten attendees each time. Therefore, there is a diverse and variable range of problems, solutions and expertise. It may be easy to think about how the more experienced members of the group are better positioned to offer advice, however, the advice of all members is valuable. Those just starting out can help those more experienced even if these newer PhD students do not always feel this way (Hefferman, 2021). For example, when I was unsure of how to express my reflexive thoughts on my methodologies in my third year, a first-year student was able to offer suggestions based on their experiences of reflexivity as a practitioner. This does not mean the experiences of those further along are not important, or help to demystify the PhD process (Ferguson, 2009), but that each member's suggestions and expertise should be recognised and encouraged. There is a different power dynamic between peers than students and supervisors which means the process of advice is less hierarchical or linear (Inman & Silverstein, 2003). Nonetheless, it can still be tricky to manage but if done successfully then the richness of advice is amplified.

My group helps to foster an environment where advice from everyone is encouraged and on reflection there are two core reasons for this: leadership and relationships. Our chair is the founder of our group and allows the discussions to organically evolve. However, she also notes down problems people bring so nothing gets missed and she draws people into the conversation. This helps to encourage everyone to contribute and for all ranges of problems to be discussed (Cantor, 2020). The chair asks every member at the beginning of each session about what they are doing, their successes (e.g. good comments on a draft chapter) and challenges (e.g. finding it hard to manage time). Therefore, the members all know each other and what each other is doing which helps them to forge connections and relationships (Denman et al, 2018). This, in turn, makes it easier to communicate, to ask the right people for advice on specific problems and give individuals the confidence to give that advice (Vincent et al, 2021).

My reflection has also shown me that it is helpful for advice to be both encouraging and challenging as long as it is constructive (Loh, 2013; Wegener et al, 2016). Challenging ideas is core to a PhD so doing this in a safe and informal environment can be a worthwhile endeavour (Loh, 2013). Challenging someone's ideas or plans can help them to test them out, clarify them and think of things differently (Wegener et al, 2016). I am a self-confessed perfectionist so challenges can make me feel uncomfortable, but it has never yet been done without a constructive and friendly tone with the only intention being to help one another. For example, I had discounted a concept linked to my wider topic and this was challenged by a person who had used it with an explanation as to why they found it helpful and a resource which explained the link in a new way. Sometimes more formal challenges are focused on the content of the work/idea, negating the

emotions experienced when received (Inman & Silverstein, 2003). The more informal relationships in my group help offer a more balanced way of delivering these challenges, which makes them easier to digest.

Reassurance

Lewinski et al (2017) suggest that imposter syndrome and doubts are commonplace for students but interacting with peers can allow students to bring these worries to a supportive group. However, it is important to note that imposter syndrome can be created when you start to compare yourself to others, which can happen in a group, as the successes of others can make a person feel inferior (Cantor, 2020). Therefore, it is important to foster supportive environments and relationships. Support groups can also be a more accessible option than discussing concerns or challenges with a supervisor due to the different relationships at play (Dericks et al, 2019).

The more formal relationships with supervisors can make students feel wary of appearing uncertain. There can also be tensions between different positions, expectations and priorities as well as time restrictions (Inman & Silverstein, 2003). I feel lucky to have supervisors who are supportive, which I know is not always the case for everyone (Nasiri & Mafakhen, 2015), but I still want to go to them with more fully formed ideas and make the most of the time we have. The group can offer advice and ideas which is helpful for this but what they can also do is reassure you that you are capable and that you are not the only one who might have had these concerns.

When I bring concerns to the group, I am met with stories of similar experiences with the addition of what they had done to overcome them, reassuring me that I too can overcome them. This works well because the group maintain a positive but realistic outlook. Members do not ruminate on the negative as this can be destructive and consuming (Boren, 2013), but they also do not offer falsehoods, which is important to keep reassurance authentic (Vincent et al, 2021). The group also celebrates and commiserates with each member which helps to bond members, building those supportive relationships (Denman et al, 2018). It also shows that we all go through setbacks and triumphs, which makes you realise you are not on your own and that you too can triumph.

Community

Undertaking a PhD can be a lonely and uncertain place, with research showing students can be isolated (Gin et al, 2021) but having a PhD community offers you social interaction and a sense of belonging (Van Rooj et al, 2021). For me isolation worked well at times, but it was also hard with no one to bounce ideas off, or to tell me my feelings were normal. I have a supportive family but that is not the same as having an academic community where people have some sense of shared experiences (Elliot et al, 2020). I have found that my group tackles isolation by offering this sense of community. However, this does not just happen by itself; communities take time to develop and evolve (Elliot et al, 2020).

At first, I felt like an outsider to my group; I was attending an already connected group of people. This was not down to the group members but barriers of my own making. I did not know what I had to offer and to me a community needs to have a reciprocal relationship between its members. Imposter syndrome frequently visits me and makes me feel like an academic fraud, as it can do for many students (Cisco, 2020), and feeling like a fraud meant I could not see myself as a contributing member of this community. This changed gradually the more I attended as I experienced compassionate people who offered comradery as well as advice. It was a safe environment, and I began to feel confident to offer my own advice. But the pivotal moment was when the chair corrected someone when they said 'your group'. They said it is not 'my group but all of ours' and I immediately agreed; discourse is so important (Boren, 2013). I felt confident to call it 'my group' rather than 'the group I attended'; I was a fully-fledged member of this community: I belonged. As with all communities, there are times where I feel more involved, contribute more and enjoy it more but I always feel a sense of belonging. It is also a nice place to be: I enjoy attending and I enjoy the company of the other members.

Collaboration

Collaboration can be of immediate benefit, such as feedback on a piece of writing (Denman et al, 2018). However, it can also have more ongoing long-term benefits. By collaborating

with others, you become more innovative with your ideas due to encountering different perspectives (Lassig et al, 2013). It can also help you to shape your scholarly identity by encouraging and challenging you as well as developing your academic and soft skills (Koris & McKinnon, 2021). It has also been shown to help students after they have graduated by building up networks, increasing social capital and developing vital skills (Pyhältö et al, 2017).

However, it was one of the benefits that I did not fully appreciate until I stopped to reflect. Organically, during meetings we collaborate to solve problems and workshop ideas, providing different perspectives and peer feedback. However, there is also more detailed and structured feedback occurring. Members will read through pieces others have written to provide feedback before submitting to supervisors or reviewers. In fact, this very article has been through that process. Some members have also joined forces to collaborate on articles following interesting discussions at group sessions. A lot of this more structured collaboration occurs outside of the group but would not occur at all without it.

Collaboration is something I was unsure of due to past experiences and wariness of criticism. However, I now realise that these issues were due to collaboration not happening with the right people, at the right time or in the right environment. If these three things are right, collaboration can help enrich what you are doing, teach you things and, perhaps most importantly, be enjoyable. I am now much more willing to collaborate, and want to seek it out, even if there seems no immediate benefit to my own work, as this 'paying it forward' (Rainford & Guccione, in press) may help me in the future and more importantly makes me feel good. It has also opened my eyes to other ways of connecting such as online networks; collaboration does not just have to be with people you are physically with or to which you have an already established connection. Inspired by others in my group, I am now exploring networks on Twitter. This is new for me and not part of my focus here, but something I am excited about and cannot resist mentioning.

Pitfalls

It may feel like I view support groups through rose-tinted glasses, but I am aware there are pitfalls. Support groups can be unwelcoming places where members can feel excluded by people who might appear or feel superior to others (Cantor, 2020). There can be toxic relationships and dynamics such as people vying for leadership (Page et al, 2019) which make people feel uncomfortable. PhD students often blame themselves for the challenges they face and do not want to appear 'weak' in front of others (Cantor, 2020). Imposter syndrome can also make people unrealistically compare themselves to other people exacerbating their feelings of academic fraudulence (Craddock et al, 2011). There is also a level of vulnerability when accessing support from peers as the lines between personal and professional/academic identities blur more than they might do when meeting with supervisors. This merging of identities can be positive and forge connections, but it can also be tricky and sometimes risky (Jordan, 2020). It is important to note that being with people does not mean you are less isolated or that all connections made will be positive; there needs to be the right kind of interaction between people (Mason & Hickman, 2019).

However, even if the relationships between people are compassionate, supportive and constructive, groups can still struggle if there is no shared goal (Ferguson, 2009). My group is diverse, nonetheless, we all have the shared goal of wanting to do our best with our studies and helping others to do their best too. This then leads to a shared session approach of updating each other, bringing problems, and offering advice. Inman and Silverstein (2003) suggest that an unstructured approach is best for groups but that they should be 'process' focused. I would also advocate for this, as in previous groups I have felt that a lack of shared approach has meant that sessions have meandered aimlessly making them a frustrating time 'cost'. A member of my group says that 'finding your village' (Rainford & Guccione, in press) is important as the people you connect with will make a significant difference to the success of these connections and I agree.

Another core issue is time: students are pulled in multiple directions with study, work and home commitments (Papen & Theriault, 2018). However, my group actually saves me time. I solve problems quicker, find resources more easily, learn skills, collaborate with others and reduce procrastination. Nonetheless, it would be prudent to remember that support can become a form of procrastination itself. As I touched on earlier, I am exploring the potentials of Twitter, but scrolling through posts can be a time vacuum. Therefore, I would recommend scheduling

support into the diary and treating it like meetings. For me this restricts the length of time I do it for but more importantly makes me treat it with the level of priority and dedication it deserves.

Despite these possible barriers I would still encourage people to give support groups a try. My reflection suggests to me that with the right people, the right approach and the right commitment, the benefits are more than worth the time 'cost', but I do appreciate that that is too simple. What 'right' means will be different for different people and at different times.

Conclusion

In summary, my reflections have confirmed to me what the literatures tells us: PhD support is beneficial. However, support can be wide ranging and by focusing on PhD support groups in my reflections I feel that this essay has been able to shine a light on the specific benefits individuals can experience when they attend these. The benefits of my group are due to the way in which the group is run and how the members approach it. My group succeeds in offering advice as all members are encouraged to ask for and give advice in a supportive environment. Reassurance works due to the relationships we have with each other and the way in which the founder chairs sessions. The group offers a community by the atmosphere created and the way in which we can all contribute. Finally, it offers collaboration with members working together both formally and informally with the goal of helping each other. However, I also needed to make a commitment to the group, if I had not overcome my preconception of the time 'cost' and whether I had anything worth offering, then I would never have started attending in the first place.

Thus, in conclusion, the literature tells us that it is not always possible to access support or experience quality when we do, but if quality support can be accessed then PhD students can find help to overcome challenges and a community to belong to, and this is exactly what I found when I accessed the support group I now call my own.

Parting thoughts

So where has all of this reflecting led me? Its intention was to offer an insight into PhD support groups and encourage people to 'give them a go' but what it has unexpectedly done is make me stand still and think about each member of my group with affection. PhDs do not need to be conducted in isolation. There is an old saying that it takes a village to raise a child and I suggest the same is true of a PhD student.

Biography

Kim Collett is a PhD student at the University of Exeter and an Associate Lecturer at the Open University. Kim's PhD is exploring the experiences of inclusion at secondary schools using the method of photo-elicitation. Her research interests lie in education, inclusion, and disability with a focus of promoting the voices of those often silenced.

References

- Allen, T.J. (2019). Facilitating graduate student and faculty member writing groups: experiences from a university in Japan. *Higher Education Research & Development*, 38(3), 435-449, DOI: 10.1080/07294360.2019.1574721.
- Bettison, E. & Haven-Tang, C. (2021). Voices of isolation and marginalisation – An investigation into the PhD experience in tourism studies, *The International Journal of Management Education*, 19(3), <https://doi.org/10.1016/j.ijme.2021.100539>
- Boren, J.P. (2013). Co-Rumination Partially Mediates the Relationship Between Social Support and Emotional Exhaustion Among Graduate Students. *Communication Quarterly*, 61(3), 253-267, DOI: 10.1080/01463373.2012.751436
- Cantor, G. (2020). The loneliness of the long-distance (PhD) researcher. *Psychodynamic Practice*, 26(1), 56-67, DOI: 10.1080/14753634.2019.1645805
- Chatterjee-Padmanabhan, M., & Nielsen, W. (2018). Preparing to cross the research proposal threshold: A case study of two international doctoral students, *Innovations in Education and Teaching International*, 55(4), 417-424, DOI: 10.1080/14703297.2016.1251331

- Cisco, J. (2020). Exploring the connection between impostor phenomenon and postgraduate students feeling academically-unprepared. *Higher Education Research & Development*, 39(2), 200-214, DOI: 10.1080/07294360.2019.1676198
- Craddock, S., Birnbaum, M., Rodriguez, K., Cobb, C. & Zeeh, S. (2011) Doctoral Students and the Impostor Phenomenon: Am I Smart Enough to Be Here?. *Journal of Student Affairs Research and Practice*, 48(4), 429-442, DOI: 10.2202/1949-6605.6321
- De Zwart, M. & Richards, B. (2014). Wi-Fi in the Ivory Tower: Reducing Isolation of the Law PhD Student Through Social Media Networks. *QUT Law Review*, 14(1), DOI: <https://doi.org/10.5204/qutlr.v14i1.524>.
- Denman, P.M., Corrales, J.M., Smyth, S. & Craven, K. (2018). From ABD to PhD: A Qualitative Study Examining the Benefits of a Support Group During Dissertation in an Online Doctoral Program, *The Journal of Continuing Higher Education*, 66(2), 106-114, DOI: 10.1080/07377363.2018.1469067
- Dericks, G., Thompson, E., Roberts, M. & Phua, F. (2019). Determinants of PhD student satisfaction: the roles of supervisor, department, and peer qualities. *Assessment & Evaluation in Higher Education*, 44(7), 1053-1068, DOI: 10.1080/02602938.2019.1570484
- Elliot, D.L., Bengtson, S.S.E., Guccione, K. & Kobayashi, S. (2020). *The Hidden Curriculum in Doctoral Education*. Palgrave Macmillan
- Ferguson, T. (2009). The 'Write' Skills and More: A Thesis Writing Group for Doctoral Students. *Journal of Geography in Higher Education*, 33(2), 285-297, DOI: 10.1080/03098260902734968
- Gin, L.E., Wiesenthal, N.J., Ferreira, I. & Cooper, K.M. (2021). PhDepression: Examining How Graduate Research and Teaching Affect Depression in Life Sciences PhD Students, *CBE—Life Sciences Education*, 20(41), 1–17, DOI:10.1187/cbe.21-03-0077
- Heffernan, T. (2021). Academic networks and career trajectory: 'There's no career in academia without networks'. *Higher Education Research & Development*, 40(5), 981-994, DOI: 10.1080/07294360.2020.1799948
- Inman, A.G. & Silverstein, M.E. (2003). Dissertation Support Group. *Journal of College Student Psychotherapy*, 17(30), 59-69, DOI: 10.1300/ J035v17n03_05
- Jordan, K. (2020). Imagined audiences, acceptable identity fragments and merging the personal and professional: how academic online identity is expressed through different social media platforms. *Learning, Media and Technology*, 45(2), 165-178, DOI: 10.1080/17439884.2020.1707222
- Koris, R. & McKinnon, S. (2021). The power of international online conversations: higher education teachers' reflections on their impact on academic development. *International Journal for Academic Development*. DOI: 10.1080/1360144X.2021.2007931
- Lassig, C.J., Dillon, L.H. & Diezmann, C.M. (2013). Student or scholar? Transforming identities through a research writing group. *Studies in Continuing Education*, 35(3), 299-314, DOI: 10.1080/0158037X.2012.746226
- Lewinski, A.A., Mann, T., Flores, D., Vance, A., Bettger, J.P. & Hirschey, R. (2017). Partnership for development: A peer mentorship model for PhD students, *Journal of Professional Nursing*, 33(2017), 363–369, DOI:10.1016/j.profnurs.2017.03.004
- Loh, P.P.Y. (2013). The enhancement of student success and engagement through collaborative student/staff online networking. *Enhancing Learning in the Social Sciences*, 5(1), 65-73, DOI: 10.11120/elss.2013.05010065
- Mason, A. & Hickman, J. (2019). Students supporting students on the PhD journey: An evaluation of a mentoring scheme for international doctoral students. *Innovations in Education and Teaching International*, 56(1), 88-98, DOI: 10.1080/14703297.2017.1392889
- Nasiri, F. & Mafakheri, F. (2015). Postgraduate research supervision at a distance: a review of challenges and strategies. *Studies in Higher Education*, 40(10), 1962-1969, DOI: 10.1080/03075079.2014.914906

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“Poem about Shut Up and Write”

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Abstract

SUAW supports a vibrant and collaborative postgraduate research culture, with the aim to supply a supportive space where peers can set aside protected time to critically reflect, and work on their research. The online aspect of the daily chat room offers greater inclusivity to the wider research community, especially though lockdown, those feeling isolated, and for remote students. The SUAW community helps peers engage with the research community by supplying short, focused study session using the Pomodoro technique of 25-minute slots to work on a paragraph, reading, thinking, planning, and as the name suggest writing. After a short five-minute break, the session repeats with another 25-minute slot of work. Sometimes a small success can be the motivation for the rest of the day. Progress does not need to be huge, but progress does need to occur, and SUAW provides this momentum. Whatever the researcher experiences, the postgraduate journey is never alone. We all share similar struggles, frustration, and ultimately success. SUAW is one approach to time management and productivity. It is a place to exchange ideas, but mostly, it is a community about getting work done. Like we often say in SUAW, each word is a step closer to your thesis. If you get the chance give SUAW a try. It might make all the difference!

Background

Shut Up And Write (SUAW) was devised in 2017 and implemented in 2018 with a grant from the University Alumni annual fund. The aim of SUAW was to develop practice, training, and resources to support postgraduate writing. SUAW remained linked with the Research Development Team, Doctoral College until it became peer led in March 2021. Below are links to articles that explain the purpose and benefits of SUAW in more detail.

<https://excellence-in-education.co.uk/finding-the-write-path-how-socially-supportive-writing-groups-help-postgraduate-researchers/>

<https://digitalculture.jiscinvolve.org/wp/2022/03/09/shut-up-and-write-online/>

Poem about Shut Up and Write (SUAW)

Shut Up And Write is all I heard,
that's great, I need to write some words.
But I'm stuck, I can't think, my mind in unravelled,
I want to write something, but the letters are scrambled.
Writing, my friend, is a road well-travelled.
Don't worry, SUAW is at hand to get you going.
You'll soon get those words without even knowing.

Welcome along to the PGR community,
no barriers, no blocks, online and accessible,
through lockdown, remote working, nothing is impossible.
Sharing experience to get motivated,
SUAW is peer support that is uncomplicated.

It started with the researcher development team,
but now it's a vibrant peer led resource,
many people run sessions to keep us on course.
The facilitators are about getting it done,
learning, inclusive, diversity, and fun.
No judgement, SUAW is for everyone.
No booking, no form, just pop in and out,
Boosting productivity is what it's about.

Collaboration, contribute, inclusion, and grow,
develops our research community via Pomodoro.
Get your ducks in a row is a popular race,

it's a 'Teams thing' so can be in any place.

Coffee and chomp are the monthly drop in,
we can have a chat with an actual person!

Hybrid retreats are a new direction,
its online, and sometimes face to face,
expanding the SUAW group, in any case.

So far so good, sounds like a hit,
everyone knows Jo made us do it!

Thinking, planning, reading, maybe meditate.
Anything but procrastinate, don't let the mind stagnate.
Be a wordsmith, step up to postgraduate.
Be yourself, tell your story, be legitimate.

Here is the magic formula for SUAW particulars,
500 words complete in one day.
2,500 words in a week, now you are well on the way.
10,000 words in just a month, and you thought it couldn't be done.
120,000 words in a year, more than a thesis, have I made that clear.

Edit and rewrite, that's what we do,
building the GW4 research portfolio.
We are creative, hard-working, and dedicated,
many have tried but SUAW can't be replicated.

So why not join us in the SUAW chat box,

one small step is better than not.
That’s all I want from you today,
have a go in this slot and start right away.
8 am to 10 pm, we are open all hours,
it’s our USP that makes you empowered.

That’s a taster of SUAW,
why not try it, you can’t go wrong.
Hey, hey, good people,
what took you so long?

Acronyms

Shut Up And Write (SUAW)

Post Graduate Researcher (PGR)

Great West Four Alliance (GW4).

SUAW Joining details

<https://www.exeter.ac.uk/research/doctoralcollege/researcherdevelopment/training/writing/shut-upandwrite/>



<https://twitter.com/SUAWExeterPGRs>



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Thank you to Kelly Preece, researcher development manager, who was the original founder of SUAW (Shut Up And Write) at the University. Extended thanks to Jo Sutherst, who is now the peer led for SUAW, and encouraged me to be part of the facilitator team and vibrant SUAW community. 'Jo made me do it'. Jo is also responsible for the SUAW word count formula.

Biography

Sam Pulman is part of the peer led facilitator team for SUAW (Shut Up And Write) often hosting online sessions and contributing to writing retreats. Sam considers the poem a team effort about quotes, support for the project, and to develop SUAW as a research tool across the wider PGR (Postgraduate - Research) community. Sam facilitated Lego Serious Play and is currently working on several mini-series to support a diversity of PGRs to explore their educational journey and aspirations. Sam is also exploring how social workers can help children to become curious and confident about being outside with nature.


Sam Pulman, Post Graduate Researcher, School of Education, University of Exeter.

SHORT ESSAY

Collaborating With Passion: Remind Me Why It Was Invited?

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Abstract

In this short essay I explore the complicated relationship between academic research and “passion” from the perspective of a confused PhD student. Passion appears to be held in high esteem across disciplines as a conduit for success (not to mention non-academic workplaces), bears at least partial responsibility for what areas of research are pursued and which are not, and is regularly given credit for major career and life choices. On the other hand, I like to think of it as a powerful but potentially toxic collaborator: It is capable of doing remarkable work and offers excellent company but if left unchecked turns into an attention-seeking git who schemes to inconspicuously take over projects with little regard for the consequences. I reflect on some of the different guises of passion to showcase its power as facilitator and antagonist of both research as a process and pursuit, and research as a career. I argue for the importance of interrogating one’s own passion and making deliberate rather than rhetoric choices about the ways in which it is allowed onto one’s (research) team.

Collaborating With Passion: Remind Me Why It Was Invited?

When you are about to step into a new culture, paying attention to anything that gives away information about its rules is vital. What do people say and do in a particular situation? What do they *not* say or do? What does that imply about what is important to them?

Apply this to the cultures of research and academia and you will find yourself in an insurmountable mess of contradictions between and within implicit and explicit rules. One of these concerns the role of “passion.”

Let’s take a step back and imagine we are starting our journey through the unfamiliar culture of academia, first as an aspiring student seeking to persuade a potential alma mater to let us into its Great Halls. We try to find out what is important to them. At the time of writing, the UCAS website explaining what a personal statement is, makes it clear that “passion” is something that universities are after: “[A personal statement] is a chance for you to articulate [...] what skills and experience you possess that *show your passion for you chosen field*” [emphasis added] (Uni-

versities and Colleges Admissions Service, 2019)¹. The closer you look, this “passion” crops up everywhere – in degree and job advertisements, in students’ and academics’ self-descriptions. And it certainly does not diminish in importance as you progress in your academic journey: The discourse of the passionate researcher is alive and well (Busso & Rivetti, 2014; Cannizzo, 2015; Lee & Roth, 2004)².

This essay is built on the observation that references to passion are plentiful in academic contexts and the ensuing desire to piece together what it means. It explores the question of what we (can) bring to the table when we are, or proclaim to be, “passionate” – to the table that is both research as an activity and academia as an institution. It presents the musings of a final year PhD student with many a decision to make about their future and with the hope that others may find something of use in these ideas.

Now let me invite you to this table where passion is waiting in the guise of several fictitious collaborators³...

Passion, the...

The Revered

It is clear that academic passion is not in it for a modest seat at the back. It is the name you drop for access. Sent by Passion, the Force to Guide Them All (but most of all, *me*). A deity with a sizeable fellowship, even in notoriously secular academia.

The Unwelcome?

What does it mean, “passion”? Consulting a dictionary as a first point of reference, we are left with the impression that the most relevant meaning is one of strong emotion, “a strong liking or desire for or devotion to some activity, object, or concept” (Merriam Webster, n.d.). A couple of things are of note here: First, we are dealing with a response that is either directly emotional (liking, desire), or at least legitimated through emotion (devotion); emotion in turn is connotated as referring to non-deliberate, non-rational, intuitive processing. Second, this response can be associated with different things: activities, objects, ideas.

Initially, this is staggering given the sciences’ traditional aversion to subjectivity and emotion (see e.g., Neumann, 2006). On a second glance however, it is not at all contradictory. If we stay with the positivist assumption underlying the (hard) sciences that there is a reality out there and that scientists are digging to uncover it, then whatever makes us dig faster, better, deeper will ultimately be beneficial. The emotion does not get in the way of discovery because the discovered is dissociated from those bearing the emotion.

The Driver

...to Success

Passion thus becomes a driver to scientific (and personal) success – it “fuels” us, makes us better tools of discovery. It is the collaborator that provides incessant motivation, wants more, prioritises The Project over The Trivial. It is tireless and does not give up easily: Passion towards an activity is associated with increased performance (Curran et al., 2015) and positioned as an integral ingredient to scientific career advancement (see e.g., Reichel, 2018).

...Who Crashed the Car

One of the problems with Passion, the Driver to Success, is how it reeks of survivor bias. Where are the stories of people being driven passionately, incessantly motivated, and powerfully headfirst into a brick wall?

¹ Note that since the point of writing the UCAS website has been updated. An archived version of the website current at the time of writing can be accessed here: <https://web.archive.org/web/20220816120334/https://www.ucas.com/undergraduate/applying-university/writing-personal-statement/how-write-personal-statement>

² Or just search for “passion” on an academic job portal of your choice.

³ These “collaborators” are abstract and fictitious and are not meant to bear any resemblance to, nor are they based on, real individuals.

Is it not passion that can make you stay up working frantically till the early hours of the morning, only to acknowledge later what could have been in plain sight all along – that the pursuit is exhilarating but the outcome is irrelevant? Is it not passion when a highly personal force directed towards a thing or activity steers us away from the consensus-built practices the scientific community relies on? Either of these scenarios (and many more) may eventually be of benefit in the longer term, yet the realities of passion as operating independently or even antithetically to whatever we define to be success remain remarkably absent when its tale is predominantly told through stories of success.

We could look at the above and say that these situations were not driven by passion. If it goes badly, it is obsession, no? To acknowledge that passion can end up in a car crash, we would either need to acknowledge that it is not almighty or that the system in which it operates cannot always do it justice or even handle it. Passion, the Revered does not like this kind of story and would like to politely request for Passion Who Crashed the Car to leave, please.

As we saw earlier, passion can relate to many things: activities, objects, ideas. But the “driver to success” perspective constrains passion to that which satisfies system requirements – while at the same time implying that passion is inherently good and objectively desirable. This creates all sorts of tensions: We end up in a situation where passion outside of these structures is effectively denied importance, existence, or legitimacy. We encourage young people to follow their passion while neglecting to mention that this will advantage those whose passions happen to fit the system. More of those later. We also end up with the implication that “following one’s passion” is equivalent, or at the very least significantly conducive to, our goals and values.

The Decision-Maker

I find this implication problematic and will make this case using my own experience. Something I would say I am passionate about are pattern-finding activities – give me a snippet of an unfamiliar language and good luck getting my attention in the foreseeable future. This passion is relatively system-conform: There are multiple activities sanctioned through our current economic and education systems that speak to it and that I am thus likely to both succeed in and that I would have a great time doing. But the more decisions I have had to make over the years, the more uneasy I have become with this passion determining my choices, even though it was often hard to put my finger on it. I have been uneasy because I came to see this passion as (despite occasionally overlapping) fundamentally independent of, and sometimes obstructive to, my ability to do what I thought was *right*.

In applying to my PhD, I made the (in hindsight not very well thought-through) decision that I did not want my passions to define who I am or can be as a researcher. I purposefully did not apply to programmes that gave me mental fireworks and instead chose a project capable of teaching me something I considered useful. I wanted to be a sensible person and keep myself away from situations that I knew would “suck me in” and sneakily lead me to prioritise passion and lose sight of my goals. Long story short, by the criteria that motivated my decisions three and a half years ago I have failed epically. This is not necessarily bad, but it makes me suspicious whenever I see passion used as a placeholder for all that is good and desirable: Can we make space to acknowledge passion as part of a process, rather than an unquestioned, omniscient, ultimate decision-maker? And crucially, can we talk about why we would ever want to prioritise a research landscape that is shaped by researchers’ passions?

The Decision-Maker’s Aide

My example was activity-specific, but other forms of passions may be directly related to one’s goals – say, a passion to end some form of injustice. The point is that it is necessary to accept passion as capable of intersecting with or being a contributor towards, but not a default equivalent of one’s goals and values. I want to respect and criticise others based on their decisions and I in turn want to be respected and criticised for my decisions. Our passions are likely to have had a say in the decision-making process (and vice-versa to a certain extent) but taking one as a shorthand for the other does not do justice to either.

The Chaotic Neutral

The above story puts passion in a worse light than it deserves. Passion can be wild and wonderful, allowing us to remain curious, explore, discover, experience joy and fulfilment. It is

erratic, often self-serving, and precedes any claim academia or the neoliberal job market put on it. When we paint a picture of passion as Driver to Success, we run the risk of forgetting not only the Driver Who Crashed but also that passion is not defined (and should not be legitimised) through its relationship with success or failure. The system of academic success we currently work in privileges passion that is failsafe: The need to continuously accrue “academic capital” (Eddy, 2006) in combination with the conventions and constraints around its accumulation does not particularly invite intellectual risk-taking (Ashforth, 2005). The wild and wonderful is invited onto Project Team Academia but please note that it needs to be house-trained prior to entry, thank you very much.

The Fluffy Blanket

Apart from chaotic energy, passion can also bring a fluffy blanket to the table: A personal place of comfort for joy and fulfilment and flow, whose positive benefits can last beyond the moment in which we engaged with it (see Curran et al., 2015).

The Sculptor

And passion can be a Sculptor, allowing us to assert part of who we are. This identity-formation component is highlighted in Vallerand et al.’s influential dualistic model of activity-related passion, where the activity becoming part of one’s self-concept is considered a core element of passion (Curran et al., 2015; Vallerand et al., 2003). How the passion activity is integrated with identity has implications for well-being, motivation, cognitive outcomes and performance: A harmonious integration where passion is perceived as an unconditional part of oneself is for instance associated with more positive outcomes than when pressures are exerted onto this integration (Curran et al., 2015).

As we have seen, by necessity some passions will be more readily compatible with or coercible into our academic rewards system than others – but we need to be clear about what we are attaching the value to. Are we valuing the pursuit or the passion that facilitates the pursuit? And, if or when, the balance is tipped in favour of the latter, how do we make sure that we do not end up declaring a passion that is an intrinsic, personal part of someone as more or less worthy than someone else’s?

The Spectres of the Past and Future

Let’s get back to the other problem briefly mentioned above: *We end up in a situation where we encourage young people to follow their passion while neglecting to mention that this will advantage those whose passions happen to fit the system.* This claim is built on three assumptions: First, in order to be passionate about something, we need to have some form of experience with it. Second, apart from regulating exposure and thereby familiarity, we have limited control over what our passions can be. Finally, passions are relatively stable over time. These assumptions are reflected in common phrases such as “finding” or “discovering” one’s passion: It is something that exists and is immutable, but you will not know it unless you make experiences with it. This is not meant to be a definition of a psychological phenomenon, but a crude attempt at disentangling assumptions we may make when talking and reading about passion in everyday life.

These points imply that we are more likely to recognise and articulate passion for things we are familiar with. Re-reading UCAS’ statement that university applicants should be passionate about the field they are applying to rings some alarm bells now. It not only endorses the idea that passion is equivalent to what is good and desirable. It also tells you that your familiarity with something is worth more than stepping outside that which you know, while implying that you know your passions because they are part of who you are. Overlay that with structural childhood and educational inequalities and it is hard to see how appeals to passion would not become complicit in solidifying privilege (see also Vázquez-Cupeiro & Elston, 2006, for a discussion on academic passion as gendered).

The Cut-Out

The final two incarnations of passion we are going to meet are some of the ugliest ones. This first one is, in fact, beautiful – it looks like all that is good about passion, an unreal mix of the intersection of passion as equivalent to our goals and values, a driver to success, both aim and

means woven into one, full of joy and fulfilment. You cannot see past its façade but every part of it says *I will stick with you, come what may*.

This form of passion smiles up from job adverts and self-descriptions: A token to signal adherence, a way of assuring that parting from this pursuit, from this job, is an affront to oneself and therefore unlikely (Busso & Rivetti, 2014). A commitment where the goal is subordinate to the pursuit, and a commitment of loyalty regardless of adversities. This form of passion is sitting dangerously close to the brink of structurally legitimised exploitation.

The Git on a Power Trip

And sometimes it confidently strides down this abyss and relishes in the power it has over you. Just a little more? We can do it. You *are* passionate, aren't you? Show it – if not to others, then to yourself. The Git on a Power Trip looks inconspicuous at the start but is slowly working to take over projects with little regard for the consequences. It keeps demanding and pushing and knows exactly what to feed you so you will work harder, put more of yourself into the pursuit until stopping is out of question. (Self-) Exploitation is legitimised through passion where research as a pursuit meets the neoliberal institution: Passion is seen as an intrinsic part of success in the activity but also serves as a rhetorical tool to justify our existence and continuation in a precarious labour market (Busso & Rivetti, 2014).

Claiming the Table

Passion can be many things. The above are some examples based on reflections and perfunctory detours into the literature: We met Passion, the Revered; Passion, the Unwelcome, who needed to justify its presence in research; Passion, the Driver to Success, who allows us to achieve and excel; Passion, the Driver who Crashed the Car, who is often invisible; Passion, the Decision-Maker, who tells everyone what to do; Passion, the Decision-Maker's Aide, who likes to chip in but stays off the steering wheel; Passion, the Chaotic Neutral, who is wild and free; Passion, the (purveyor of a) Fluffy Blanket; Passion, the Sculptor, who lets us assert who we are; Passion, the Spectres of the Past and Future, who haunt the future with the status quo; Passion, the Cut-Out, who is unconditionally loyal; and Passion, the Git on a Power Trip, who is ready to exploit.

Passion can be complicated and being able to live your passion, and even get paid for it, is a huge privilege. Academia wants us to believe that we can achieve it. A big challenge in negotiating this belief is to recognise the overlap and tensions between the complex realities of passion, the realities of academia as a workplace, and the glorification of a tokenised academic passion.

Part of these tensions lies in the apparent correspondence between passion and success: Repeating stories of passion as a prerequisite to success suggests that passion is and should be a decision-maker, while side-lining that motivation to pursue a goal may come from elsewhere, and at the same time leaving little space to acknowledge that passion is not a safeguard to failure.

The image of the passionate academic not only conveys this message that passion is integral to success in research (and thus the academic workplace), but also positions research as an endeavour that is built on *individuals'* characteristics and commitments (Ashforth, 2005; Busso & Rivetti, 2014). A collective appreciation of passion in research as something that does not necessarily (need to) align with the structures of the academic job market, but that is – and is allowed to be – wild and erratic, may go a long way to opening up new perspectives, giving the opportunity to learn from failures that we would otherwise not have access to, and de-individualising practices that need not, or even should not, be person-bound. Ultimately this would necessitate rethinking academic reward structures as much as our frequent rhetoric uses of “passion.”

Back to our original question: Why was (or is) passion invited? This reflection gave a crude stab at some possible answers for why we need to deal with passion as something academic environments keep inviting to our table, and as something that we bring to it ourselves. The key is knowing who is at our table at a given time and why – and, if we can, influencing who we extend our invitations to.

Biography

Johanna is a final year PhD student at the University of Bath who is interested in too many things. Her thesis focusses on people's engagement with public health maps.

References

- Ashforth, B. E. (2005). Becoming Vanilla Pudding: How We Undermine Our Passion for Research. *Journal of Management Inquiry*, 14(4), 400–403. <https://doi.org/10.1177/1056492605280783>
- Busso, S., & Rivetti, P. (2014). What's Love Got to Do with it? Precarious Academic Labour Forces and the Role of Passion in Italian Universities. *Recherches Sociologiques et Anthropologiques*, 45(2), 15–37. <https://doi.org/10.4000/rsa.1243>
- Cannizzo, F. (2015). "The Passion to do it": Exposing Academia's Love Affair with Neoliberalism. *TASA Conference Proceedings*. https://www.researchgate.net/profile/Patrick-Okeeffe/publication/319523478_Efficiency_productivity_and_fairness_An_analysis_of_the_Harper_Review_into_Australia's_competition_policy/links/59d465b9a6fdcc181ad95e9a/Efficiency-productivity-and-fairness-An-analysis-of-the-Harper-Review-into-Australias-competition-policy.pdf#page=41
- Curran, T., Hill, A. P., Appleton, P. R., Vallerand, R. J., & Standage, M. (2015). The psychology of passion: A meta-analytical review of a decade of research on intrapersonal outcomes. *Motivation and Emotion*, 39(5), 631–655. <https://doi.org/10.1007/s11031-015-9503-0>
- Eddy, M. D. (2006). Academic Capital, Postgraduate Research and British Universities: A Bourdieu Inspired Reflection. *Discourse: Learning and Teaching in Philosophical and Religious Studies*, 6(1), 211–223. <https://doi.org/10.5840/discourse20066117>
- Lee, Y.-J., & Roth, W.-M. (2004). Making a Scientist: Discursive 'Doing' of Identity and Self-Presentation During Research Interviews. *Forum Qualitative Social Research*, 5(1), Article 12.
- Merriam Webster. (n.d.). *Definition of PASSION*. Merriam Webster. Retrieved 5 August 2022, from <https://www.merriam-webster.com/dictionary/passion>
- Neumann, A. (2006). Professing Passion: Emotion in the Scholarship of Professors at Research Universities. *American Educational Research Journal*, 43(3), 381–424. <https://doi.org/10.3102/00028312043003381>
- Reichel, J. (2018, August 31). Want to succeed in research? Passion is key! *ECR Community*. <https://ecrcommunity.plos.org/2018/08/31/want-to-succeed-in-research-passion-is-key/>
- Universities and Colleges Admissions Service. (2019, December 19). *How to write a UCAS Undergraduate personal statement*. Retrieved September 11, 2022, from <https://www.ucas.com/undergraduate/applying-university/writing-personal-statement/how-write-personal-statement>
- Vallerand, R. J., Blanchard, C., Mageau, G. A., Koestner, R., Ratelle, C., Léonard, M., Gagné, M., & Marsolais, J. (2003). Les passions de l'âme: On obsessive and harmonious passion. *Journal of Personality and Social Psychology*, 85(4), 756–767. <https://doi.org/10.1037/0022-3514.85.4.756>
- Vázquez-Cupeiro, S., & Elston, M. A. (2006). Gender and academic career trajectories in Spain: From gendered passion to consecration in a *Sistema Endogámico*? *Employee Relations*, 28(6), 588–603. <https://doi.org/10.1108/01425450610704515>

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The Collaboration Pyramid – Inspiring Radical innovation That People are More Willing to Adopt

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Abstract

Innovation is a paradox. On the one hand its benefits are manifest, but on the other, achieving those benefits is problematic. This research paper argues that we have been looking at innovation the wrong way. Instead of focussing on new products and processes, innovation should first seek to understand why people change. It introduces the collaboration pyramid, a model that sets out five different ways of thinking essential to successfully gain the intersubjectivity needed for the effective motivation of key stakeholders to adopt new practices. The model is derived from socio-cultural theory and brings together strands of older cultural psychology with recent advances in cognitive psychology that shed new light on situated learning. The research was inspired by scholars' resolutions to the "learning paradox", which argues that because learning is situated, it is impossible to learn new things that lie totally outside of our experience. Drawing on the work of the educational psychologist Carl Bereiter, the cultural psychologist Michael Cole, the creativity expert Keith Sawyer, as well as practitioner literature, the paper demonstrates how multi-disciplinary thinking can stimulate the emergence of new and better ways of seeing the world. The theoretical process is illustrated through two case studies from very different contexts that are researched through co-created autoethnography.

This paper makes an original contribution by drawing together diverse threads spanning economics, educational, and cultural/cognitive psychology to explain the challenges of effective innovation practice and describes how they might be overcome with reference to case studies.

The Imperative to Innovate

Imperatives ranging from entreaties to boost productivity and increase economic growth (OECD, 2015), through to public sector urgings to put citizens at the heart of public innovation as a force for change (Harris & Albury, 2009) extoll the virtues of innovation. These epitomise a broader range of organisations, consultancies, NGOs, and researchers all arguing that innovation will make things better. In the seven years since the OECD's paper, productivity in the G7 group of leading economies fell with the UK declining among the fastest (Harari, 2020). Public

services performed no better. An Institute of Government report argued that despite a broad consensus on the need for joined-up Government, nobody quite knows how to achieve it (Wilson, Davison, Clarke, & Casebourne, 2015). Bason (2022) goes further insisting that few public sector organisations today could develop the kinds of radical new solutions that are needed.

Bason (2022) and Blank (2019) identify process as a key culprit. Today's drive for efficiency and quality at scale calls for finely tuned processes that resist change. (Martin, 2019). Initiatives like six sigma aim to reduce variability (Theisens, 2021). Because of its experimental and iterative nature, innovation is inherently inefficient and cannot be scaled until a saleable product emerges. Few of the initiatives, reorganisations, hiring in consultants, and off-site creativity sessions produce positive outcomes (Blank, 2019). These experiences portray innovation as a highly risky venture, exacerbated by conventional wisdom that suggests failure is a necessary part of innovation. It is little surprise then, that innovation is mistrusted. People see it as either a futile gesture, or, worse, a directive from on high to do more with fewer resources to the detriment to staff wellbeing (Bryson, Dale-Olsen, & Barth, 2009)

It Does Not Have to Be This Way

This paper argues that we can deliver successful innovation outcomes at scale and provides supporting examples from both public and private sector. The challenge is that the route to success defies conventional wisdom. To really understand the process requires a paradigm shift in our conceptualisation of innovation. We need to move away from the traditional view of breakthroughs leading to sudden insights, replacing it with a more organic transformation where promising new ideas emerge through cross-domain collaboration (Moran, 2009). Changing the unit of analysis away from novelty to adoption, focuses on why its intended audience will work in the new ways innovators intend (Neild & Seymour 2021). After all, how great is an idea that nobody believes, a product that nobody buys, or a process that people eschew? Inspiration for this shift comes from Sawyer's (2012) sociocultural definition of creativity that emphasises appropriateness to its intended audience at least as much as its novelty.

The reconceptualization does not end there. Much of the research on innovation emanates from business schools and is often deeply grounded in economics orthodoxy such as rational choice theory. Despite being a social science, business research adheres to the positivist epistemology of the natural sciences. Former Bank of England Governor Mark Carney in his 2020 Radio 4 Reith Lectures acknowledged that: *“economists, myself included, generally suffer from physics envy; we covet its neat equations and crave its deterministic systems and this inevitably leads to disappointment. The economy isn't deterministic people aren't always rational, human creativity, frailty, exuberance, and pessimism all contribute to economic and financial cycles. As a great physicist, Isaac Newton lamented, I can calculate the motions of celestial bodies but not the madness of people.”* (Carney, 2020).

Carney's remarks help explain why among the first people to warn of the 2008 financial crash was an anthropologist not economist or banker. Tett (2021) describes blindness in the financial services eco-system to the mounting risks inherent in the financial instruments driving banking profits. Her observations parallel the pervasive culture that impedes innovation – a culture so invisible that those closest to it completely miss it. The next section offers a deep dive into the socio-cultural theory that underpins this main argument. After that, comparing theory with observation suggests a best practice model for radical innovation.

A deep dive into sociocultural theory

Sociocultural theory posits that it is impossible to understand human behaviour and learning without also considering the social and cultural environment that shapes it. Its origins can be traced to the influential work of Russian developmental psychologist Lev Vygotsky in the early 20th century. More recent scholars have refined and developed it including the concept of prac-

tice popularised by French philosopher Pierre Bourdieu (1977) and described as “the corollary of the neglect of the social conditions in which science is possible”. Sociocultural theory explicitly recognises the epistemological validity of human subjectivity.

Mind, Society and Cultural Psychology

The story starts with Vygotsky’s *general genetic law of genetic development* (Vygotsky, 1987) which argues that human development occurs in two stages: first, on a social level, and second, on an individual level. These two levels will be unpacked in the next subsection. Cultural psychology “emphasises contextual mediated action”, which essentially means that humans interpret their sensory input through the lens of prior experience. It also assumes that “mind emerges in joint mediated activity” – meaning that our understanding is co-constructed with those around and is “situated in practical activity” (Cole, 1996, p. 104).

According to Cole and Vygotsky, no matter how much we may think we learn on our own and our brains process an objective view of reality, everything we perceive is filtered through a cultural lens shaped by previous interactions with our environment (in its broadest sense). This has profound implications that help explain Mark Carney’s lecture. It is undoubtedly convenient to think of people as a broadly homogenous group whose behaviours can be scientifically predicted as rational actors. This gross simplification almost inevitably leads to disappointment.

Instead, understanding people requires appreciation of the current and historical contexts that make them who they are. Why do we eat what we eat, wear what we wear, and do as we do in our leisure time? All these activities have been shaped through interactions with family, friends, or external media. Think of a noun that you have recently read. What rich picture does it conjure up? A simple three letter word like cat might trigger thoughts of the family pet, an image from a film, or even a phobia based on a particularly frightening early life experience. Therein lies the problem. Short of living somebody else’s life or some highly intrusive snooping, how can one possibly understand what shapes people’s habits, preferences, and the way they see the world? This is the meaning and implication of contextual mediated action. The influences which shape how we make sense of lived experiences are just as hereditary as our physical DNA.

Given the above, it is a wonder that any new products or processes achieve significant levels of adoption. As Cole (1996) identified, the mind is *co-constructed through joint mediated activity* or as Vygotsky put it, on the *social level*. Without co-constructed mind, we could never advance much beyond basic motor skills acquired through trial and error, much like apes lacking *higher mental functions* (Vygotsky & Luria, 1930). We could never learn from things outside of our immediate experience; standing on the shoulders of giants would be entirely beyond us (Vygotsky & Luria, 1930). This “learning paradox” (Daniels, 2016, pp. 32-35) introduces the specific challenge for innovation. How do we learn about something that is yet to exist? If learning is situated in the context of our environment and our past experiences, how do we create entirely new knowledge? Theoretically, human progress seems impossible, yet observation makes progress undeniable. Before resolving this paradox, we need to better understand the process by which we learn.

Intersubjective Learning

This section starts by examining in more depth the distinction between instruction (social level) and development (internal level) introduced earlier. “We have seen that instruction and development do not coincide. They are two different processes with complex interrelationships” (Vygotsky, 1987, p. 212). It is worth noting that “internal” does not exclude context as some scholars have concluded, but rather describes how we remember. This way of thinking is consistent with more recent advances in cognitive psychology including *distributed cognition and situated learning* which argue that the human mind cannot be considered to exist entirely within a person’s head (Cole & Wertsch, 1996).

Revisiting the three potentially different perceptions of cat, what accounts for the difference? Cultural Mediation describes how we make sense of and catalogue our experiences. Mediating artefacts include family traditions films, or concurrent emotions. They translate objective physical experiences into subjective memories as illustrated below.

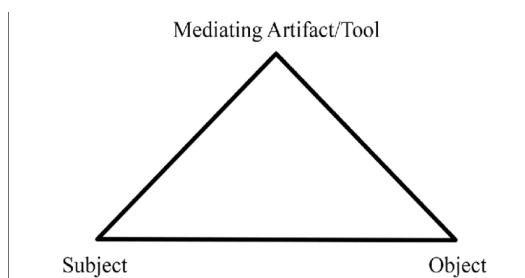


Figure 1: Cultural Mediation

Adapted from (Cole 1996, p104)

Were you asked to perform some grooming activity on our unspecified cat, depending on your subjective perspective, you may regard this as something you habitually do, something you have never done, but could work out, or with some alarm requiring help. This simple example illustrates the processes involved, but says little about learning, except by introducing everyday concepts as habits, which are the product of the learning process. Vygotsky (1987) distinguishes between everyday spontaneous concepts and scientific or abstract concepts in two ways.

Problems that involve everyday concepts can be solved spontaneously, while scientific concepts require a teacher's assistance (Vygotsky, 1987). Everyday concepts are personal, falling outside any definite system. Scientific concepts are generalised into an organised system (Vygotsky, 1987). Everyday concepts are self-catalogued because they need no reference to others. If you have ever struggled to explain how or why you do something because it is just a habit, then you will have experienced an everyday concept. To explain or teach something to somebody else requires intersubjectivity. Wertsch (1985) explains intersubjectivity in terms of interlocutors sharing aspects of their *situation definitions*. Typically, this definition overlap may occur on several levels and hence several levels of intersubjectivity may exist (Wertsch, 1985).

Wertsch (1985) describes three stages of moving between 'everyday' and *scientific* concepts. In the first "*unorganised heaps*" stage, systems are highly individually catalogued according to a personal world view and appear entirely random to anyone else. In the second "*thinking in complexes*" stage, the system moves from the subjective to the objective. Another person can understand the system, but it remains rooted to the original context, enabling a solution to the specific problem at hand, but not a process generalisable to other contexts. Stage three distinguishes between this *pseudo-conceptual thinking* and *conceptual thinking*. In the former, subjects just know what to do in this case. In the latter, subjects know what to do, but crucially also why they are doing it that way. The essential difference is that the former can perform an activity by rote while the latter requires mastering the system of logic behind the activity; they understand it structurally. Conceptual thinking is possible only when decontextualising away from the experience that initially created and catalogued the memory (Wertsch, 1985). Thinking back to the semiotic meanings people might ascribe to cats described earlier, intersubjectivity would allow a person to empathise with those who loved, hated, or feared cats by generalising the concept of cat beyond their own individual experience of them. Decontextualising makes processes portable or generalisable to unrelated contexts. Since portability is crucial to innovation, we will discuss it later. Meanwhile, let us illustrate this complex thesis through reference to learning to drive in the hope that the experience for most readers is sufficiently similar for the example to resonate.

Early on, we were given pseudo-concepts such as which gear corresponds to which

speed band. This enabled us to change gear by rote, reducing the cognitive load. Initially, every manoeuvre required thinking about, but with practice, skills became embedded in the subconscious until we could comfortably drive in the appropriate gear without much thought. For experienced drivers, cognitive processing is very much in the background, literally out of mind. Cognitive sophistication only becomes apparent when brought to mind. While driving an autonomous vehicle, I was surprised by the car suddenly applying the brakes. My brain had subconsciously catalogued a car crossing the road at right angles ahead as no danger. The autopilot software alarmed at the rate of closing had not figured that the crossing speed meant it would pass well clear. Posed as a geometric (scientific) problem to solve, I would have struggled in the moment, but mental heuristics recalled previous experiences as safe. Simon (1996) describes in some detail the computational cognitive limits of the human brain. Another brief but influential paper from two psychologists commissioned by the US Military describes human decision-making in conditions of uncertainty (Tversky & Kahneman, 2004). Their paper “*shows that people rely on a limited number of heuristic principles which reduces the complex tasks of assessing probabilities...to simpler judgemental operations*” (p.1124).

Heuristics help everyday life by providing shortcuts in decision-making, but also lead people into making poor decisions or perceiving something not there, should the shortcut not fit that context. Heuristics cause optical illusions, where experience leads the brain to interpret visual stimuli in a way unrelated to physical reality. Pertinent to the current discussion is the *Availability Heuristic* (Tversky & Kahneman, 2004) in which people judge the likelihood of something happening by the ease with which instances are recalled. This induces bias in favour of the memorable. These studies only partially distinguish between conscious and sub-conscious thought. More recently scientists have discovered how much decision-making takes place in the sub-conscious. A New Scientist article put the figure as high as 95% (Young, 2018), with 40% of our decision making driven by habit. Buying decisions are similarly and invisibly associated with unrelated cues. In deciding which restaurant people stop at for an unplanned meal, people make snap decisions simply based on first impressions from outside (Simester, 2016). This is consistent with the *Associative Heuristic* (Tversky & Kahneman, 2004) which is another shortcut in which the brain makes assumptions about the unseen based on previous examples of the association between first impressions and later experience. These show how powerful and sophisticated unconscious cognitive processing can be even if the conscious mind is not immediately aware of it, (Bargh & Morsella, 2008), flagging our attention only to dangers we need to be aware of. Because heuristics are situated entirely in past experiences and not present sensory input, they can let us down. This is a particular problem for innovation when going beyond our previous experiences and can be exacerbated by group think within Communities of Practice (CoP).

Radical Innovation, situated learning and Communities of Practice

Lave and Wenger’s (1991) derived their seminal work from socio-cultural theory, building on social learning that is situated in the context in which it is practiced. It describes how newcomers start out on the edge of a community of practice, “*legitimate peripheral participation*”, earning passage to the centre by learning the practices of the community and forming relationships and position through participation (Lave and Wenger, 1991, p. 111). CoP typically consist of three core elements, which are broadly self-organising:

- Knowledge domains setting clear scope boundaries of interest shared among members
- Communities motivating members to contribute to something larger than themselves
- Practice sharing tools and techniques among the community making it more effective.

Lemke (1997) asks “What kinds of learning can take place wholly within a single community of practice and its activities, and what kinds require journeys that must take us also into others?” (p4). Norman and Verganti (2014) provide an answer in a paper arguing that no radical innovation was ever designed. Norman and Verganti (2014) define “Incremental innovation: improvements within a given frame of solutions ... (i.e., “doing better what we already do”); and Radical innovation: a change of frame ... (i.e., “doing what we did not do before” (p 82). Substituting the word frame for practice in both definitions suggests that CoP only support diffusing improved ways of working and pursuing incremental innovation. Bereiter (1997) develops this thinking a stage further arguing that the main weakness of situated cognition is precisely its situatedness. Status (social and symbolic capital) in the community accrues with expertise. The more central somebody becomes in the community, the higher in the hierarchy they climb. But as status and expertise grow, so does situated cognition, making it ever harder to set that expertise aside to “do what we did not do before” (Norman & Verganti, 2014 p. 82).

Overcoming situatedness and resolving the Learning Paradox

A traditional learning environment has a syllabus with defined and assessed learning objectives. Knowledge is transferred rather than created. Even in most research, knowledge is out there, but it needs to be discovered, synthesised, or proven. In radical innovation, pre-existing answers do not exist; whatever the solution turns out to be, it has not been done before. Otherwise, it would not be radical. Knowledge evolves through the process and may be entirely different to that envisaged at the outset. We create new knowledge objects (Bereiter, 1997) in the form of trade secrets, patents or published work. This leads neatly on to the learning paradox: “that if one tries to account for learning by means of mental actions carried out by the learner, then it is necessary to attribute to the learner a prior cognitive structure that is as advanced or complex as the one to be” (Bereiter, 1985, p. 202). Again, this implies that situated learning prevents learning wholly new things, which we know to be untrue. Beyond the intellectual curiosity of this paradox, scholars’ proposed resolutions cast light on two possible processes for radical innovation defined below using the terms *Emergence* and *Abstract Generalisability*.

Emergence arises through combining simpler structures into more complex ones in ways that could not be deduced from even a complete study of their component parts (Sawyer, 2003). It is a form of social constructionism that combines individual constructivist realities into new ways of working that no individuals would have conceived on their own. Emergence does not in itself, overcome situated cognition, but shows that the broader the situation, or the greater the diversity of interacting individual experiences, the greater the likelihood of novelty in the emergent product. The mistake is to assume that novelty is the end game for innovation. Broadening the domain through diversity or using creative ideation approaches may result in greater novelty but also risks losing focus. Creating new products that are appropriate to nobody offers little incentive beyond idle curiosity for users to try them. For widespread adoption we need to bridge the chasm between novelty and pragmatic value creation (Moore, 2014).

Abstract Generalisability seeks to overcome the situatedness Bereiter (1997) views as the problem. Vygotsky’s (1978) *scientific concepts* overcome situatedness through decontextualization by allowing words to become abstract representations of multiple culturally mediated experiences rather than tied to the experience that first brought them into the mind. Wertsch’s (1985) elaboration of this concept using intersubjectivity provides a clue to how we can generalise knowledge from one context to another to transfer knowledge from teacher to learner. Bereiter’s (1997) own resolution and that of Quartz (1993) argues that computer programmes are symbolic models of real situation but cannot themselves be situated; changing the input variables changes the situation. In this respect, a computer programme inhabits Popper’s third world (Bereiter, 1997). Popper (1978) defined three worlds. The first world is physical objects, consisting of everything that can readily and objectively be observed whether living or inanimate. The second world consists of subjective experiences, psychological thoughts, and feelings. World

three contains human creations such as works of art, literature, and scientific theories (Popper, 1978). *World three, immaterial knowledge objects* transcend the subjectivity of their creation because their meanings can be analysed and tested through empirical means in a way that world two subjectivity cannot. Newton's laws of motion transcend situatedness because they apply in virtually every context even if for practical purposes usually in a specific situation. This contextual transcendence makes them useful in radical innovation *to do what has not been done before* like landing a man on the moon.

Purists might argue that Abstract Generalisability is not really doing what has not been done before because the knowledge already existed in a different situation. This is fair, but consider the iPhone. To phone users, a phone without keyboard for dialling calls was radical. To iPod users, adding phone functionality to their music players to allow them to download music away from WiFi was incremental. In keeping with Norman & Verganti's (2014) definition, the iPhone required mobile phone users to *reframe* their conception of the term mobile phone. The term smartphone helps change the *situational definition*. Sociocultural theory helps us understand why customers may not buy new products and services, that offer significant value simply because their brains cannot make the leap from one situation to another. Intersubjectivity helps bridge that leap as shown in the case studies.

Methodology and Limitations

This paper offers highlights from a larger research piece seeking to enhance the development of radical innovators, by treating innovation as a learning journey towards realisation. The methodology derives from Heidegger's *Hermeneutic Phenomenology* (Polt, 1999), interpreting the lived experience of innovators, seeking insights from customer research. Data was gathered primarily from the reflections of students studying innovation at the University of Bristol across eight new ventures and 34 assessed individual reflections on the lessons learned from venture creation across three masters level programmes. One case study (the second in this paper) was co-produced with Public Health England. The main research method was co-produced autoethnography (Kempster & Iszatt-White, 2013) synthesising data through a process of meaning making as students reflected on their innovation journeys. The study's aim was to improve teaching practice by reflecting on how students interpret what is taught, assimilate it into their practice, and how that is influenced by cultural norms.

The two case studies presented in this paper were selected to provide a contrasting range of phenomena to examine and show how the conclusions derived transcend specific contexts. In the broader study, the case studies were not deliberately planned to maximise generalisability, but rather were topic areas chosen by the students. The criteria for selection were the rigour of their research and how convincing a case they made for their proposition. As such, there is no claim that the conclusions can be universally applied. Using student assessed material as data naturally limits the range and scope of material studied, but empowering students to comment on what they find interesting or challenging provides enlightenment on areas that otherwise may have escaped the spotlight. The empirical parts of this paper aim to be descriptive rather than explanatory and make no claims to validity. If they resonate with readers' experiences, it will have served its purpose.

Applying theory to the practice of innovation

Vygotsky's body of work largely concerned the mental development of children, but his insights into the mind excellently illustrate the challenges and opportunities for innovation today. What you and I see and understand when we gaze on the same object may be entirely different. A product that benefits me hugely in my context, might be worse than useless in yours. Recognising these differences in perspective and how to bridge them goes a long way to solving the

challenges to successful innovation. Recognition provides a foundation for empathy (shared understanding) with prospective customers and intersubjectivity (shared meaning) to bridge their respective situations. Neild (2017) describes the challenges of *taking magic to market*, for new “magic” leggings made from innovative materials that help athlete’s muscles recover quicker and perform well for longer. This technology offered substantial and legal enhancement to athletes’ performance. Customers could not see the benefits because the proposition offered an eloquent description of science, which few customers read. They saw non-branded kit at a premium branded price. A short video interview with a rower that loved the leggings provided the breakthrough. Describing how the magic leggings made her feel as fresh in the third race as the first was something that rowers could relate to; sales took off.

There are three things to note here:

1. Intersubjectivity provided a bridge transcending the separate practices of rowing and materials science. Customers rarely care about science; preferring something relevant.
2. The subjective research method empowered the rower to choose words which would never have occurred to the innovator.
3. This was radical innovation. To most, that leggings could improve performance in this way was inconceivable. Reframing it as a performance enhancing tool, doing things that leggings had not done before made the proposition more obvious.

Some useful tools can build intersubjectivity with customers. Frameworks like “*jobs to be done*” (Ulwick, 1996) and (Christensen *et al*, 2016) offer a way of positioning propositions from customers’ perspectives. Discovering customers’ *unmet needs* (outcome thinking) can uncover better ways of meeting needs by reframing the problem away from the situated constraints of existing solutions. However, motivation for the outcome must exceed the friction impeding switching for a new way of working to prevail. Intrinsic motivation is more effective than extrinsic motivation (Kuvaas, 2018) and emotional outcomes can be far more compelling than rational ones (Magdis, Zorfias & Leemon, 2015). Such insights rely on subjective rather than objective research methods but can move a proposition from kind of interesting to compelling by framing the opportunity in terms that most motivate customer action.

Neild’s (2017) phrase “taking magic to market” is deliberate. Magic is associated with tricks which is often how customers’ see radical innovations. When taking customers on a journey outside their experience, their sub-conscious will rebel. They need help on that journey not signposting to an inconceivable destination. In Henry Ford’s much quoted case, customers could not conceive of cars as the solution to the problem of wanting faster horses. At the time, most people saw cars as rich people’s playthings, not commercial transport. (Neild & Seymour, 2021). Both radical cases were inconceivable; performance enhancing leggings and affordable cars seemed too good to be true. But reframing made the propositions obvious.

How does socio-cultural theory help with this?

Intersubjectivity through co-production evolves directly from *cultural mediation*, illustrated in Figure 1. Co-mediation allows innovators to customise portable solutions to improve customer’s lived experience, prompting the emergence of a contextual experience that neither party envisaged. This process is illustrated in Figure 2 below.

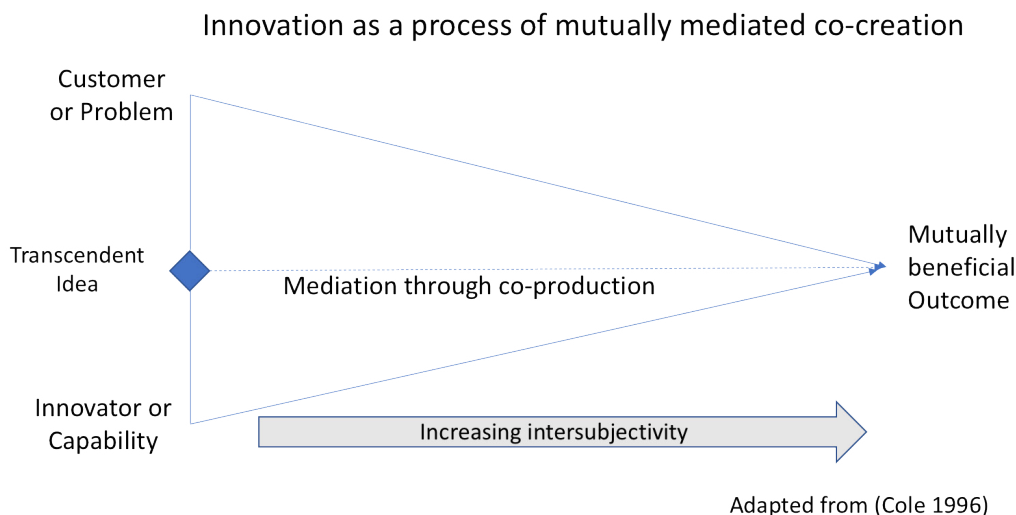


Figure 2: Innovation as mutually mediated co-creation

Case Study One: Combination Creativity in Artificial Animation

This case shows radical innovation in practice by two final year computer science with innovation students at the University of Bristol. They co-produced a radically new way to computer generate 3D rendered animation from 2D assets with Aardman Animations. Direct transcripts of the interview are shown in italics. Kaedim (2020) was formed to commercialise the emerging technique.

Computer science studies demonstrated how *difficult and repetitive is the process of creating animations*. They wondered if *this might be a problem that other people were also facing*. Their research revealed *different ways people are trying to solve this problem finding difficulties that have not really been solved yet*.

Inspiration came *from academic researchers who did nothing with it once published who operated completely in siloes*. *You have designers very skilled in design software, and machine learning engineers very skilled in machine learning, who never talk to each other*. *Timing also contributed as machine learning has developed fast in five years*.

Lab research highlighted a possible solution, but *how can we adapt and improve it to make it useful?* Co-producing with Aardman Animations, they explored ways to turn 2D images and archive objects into 3D assets. Aardman had no in-house machine learning expertise to develop useful tools. The technical risk and costs to hire machine learning engineers made the idea inconceivable. But if Kaedim take on that risk, Aardman benefit hugely if it works out (Kaedim, 2020)

For Kaedim to acquire the data needed to develop and test algorithms would cost more money than they had. *The data allows us to develop our technology to the point where we have proven that it can do this stuff, and then we can take it to other people and say, we've proved it with Aardman*. *Because we're not just two masters students doing a project, but working with Aardman, others should take us seriously* (Kaedim, 2020).

In this example of mutual mediation, Kaedim had a potential solution to a problem that they guessed Aardman might be experiencing but had no idea. It never occurred to Aardman such a solution might exist, so they were not looking for it. Any attempt to sell a machine learning solution to an animator would likely fail because it falls outside their experience and would be categorised as irrelevant by the sub-conscious. By co-producing terms of reference for an innovation project, both parties gained value that was mutually beneficial as illustrated below.

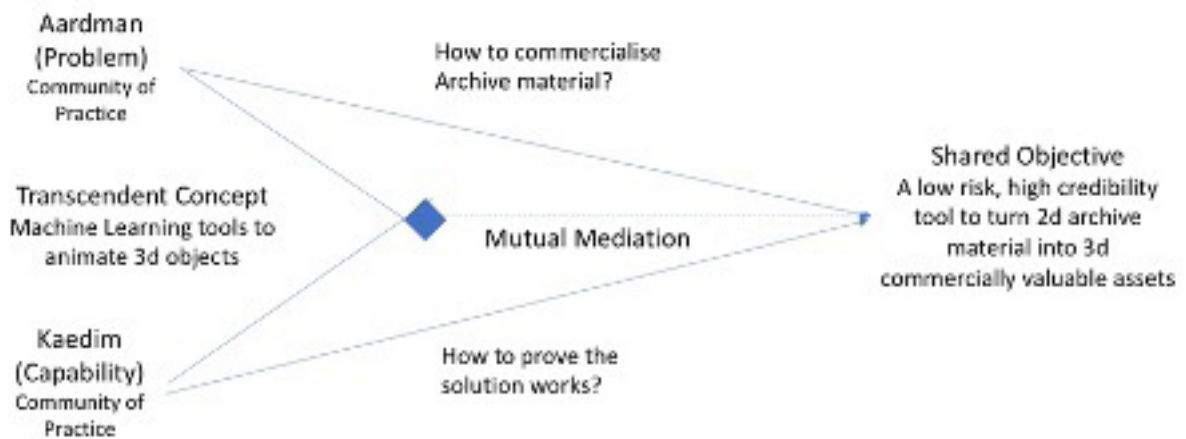


Figure 3: Co-producing problem and use case

Aardman’s problem (commercialisation of archive assets) sits within an animation community of practice and Kaedim’s capability (machine learning) in a computer science community of practice. Kaedim and Aardman co-produce intersubjectivity by seeking a mutually beneficial outcome (3D digitisation of archive data). This outcome served different interests for each. Kaedim gained access to data and social capital from working with Aardman for Kaedim to prove the solution. Aardman got access to low-risk high value expertise for free. This outcome made sense to both parties because the same outcome achieved different objectives for each party.

The outcome is enabled using *decontextualized knowledge objects* by applying *analogical thinking* (Kim, 2017) to generic problems derived from industry conferences and research papers to produce a potential solution that transcends the individual CoP. This process is illustrated below in figure 4.

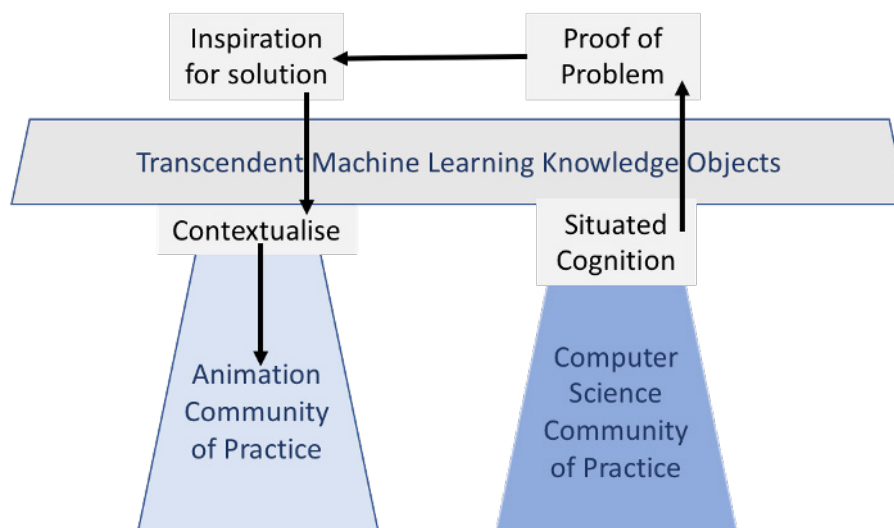


Figure 4: How radical innovation transcends communities of practice

For Aardman, the perceived problem was not that they lacked machine learning expertise because the significance of that expertise was not immediately apparent. Kaedim could never have pitched a product because at the time all they had was an idea. Nonetheless, the problem was sufficiently acute for Aardman that it was worth their while investing resources to discover if a solution was feasible. Through discussion, an appropriate context emerged. By working with archive footage, the risk was reduced for both parties.

Co-creating contexts for the commercial application of generic tools and techniques learned

in Higher Education can do a lot to move innovation forward. Universities often have solutions looking for problems while organisations have problems that those solutions can be adapted to address if only, they can be framed in the right context. These findings accord with ethnographic researchers observing how opportunities arise in practice (Sarasvathy & Venkataraman, 2011). Their study concluded that while successful entrepreneurs co-produced opportunities with stakeholders, MBA students did not. There is much yet to do in entrepreneur education.

This case applied solutions that were out there into a radically new context (from academic theories to practical application). It is an example of *Abstract Generalisation*. The next example is *Emergence*, looking at co-creating wholly new ways of working for adult social care. It was produced from written material and the finished text was then approved by a representative of Public Health England.

Case Study Two: Co-creation Transforms Complex Needs Provision

The need was initially triggered by funding, however, the services delivered did not have the expected positive impact. Historically, service users had been referred to a lead organisation and “labelled” to define user’s entitlement to services. Often the labels were wrong. Not wilfully, but simply because a single organisation had a single perspective, while those with complex needs defied easy categorisation. Data protection concerns and commissioning practices meant that multi-disciplinary working was the exception. Indeed, the combative and competitive nature of the procurement process had unintended consequences with suppliers defending their positions rather than working for the best patient outcome. They had little idea of what other suppliers offered and neither mechanism nor incentive to cross refer. Users felt *done to* rather than *worked with* while staff were not well trained in many of their needs. In some cases, there was a complete mismatch between what providers offered and what users really valued.

Things needed a radical overhaul, but nothing they had tried so far made much difference. The only way forward was co-production. The challenge was how. Co-production involved getting users, specialists, providers, and commissioners together through a whole variety of mechanisms to better understand each other’s perspectives. Unlike a consultation, where an arms-length team asked questions and wrote a report, this was broader, deeper, and far more collaborative. The process started in 2012, looking at over 70 services involving over 400 people. It covered users and carers through to senior decision makers. People’s views were important, and whitewash was discouraged. But uncomfortable truths, shattered preconceptions, and very awkward moments for participants threatened the whole process. Through close collaboration, a clear picture of the problems emerged. There was equally clear consensus around the vision, a whole system of service designed around the needs of people, rather than a fragmented market built around the needs of commissioners and service providers. Such Utopia seemed inconceivable. Most providers already thought they were doing the best they could possibly do under the circumstances. In hindsight, this was the obvious solution, and the only way things would ever be substantially better, but it was only made possible by involving everyone.

A lot needed to change. Senior managers needed to recognise that the best ideas could come from the most junior roles. Procurement people needed to partner with providers rather than beat them with contractual sticks. Providers needed to take a long hard look at how well their skills fitted with what users really needed and learn from best practice. Collaboration was a strange practice that required a lot of trust to embrace. The fear, the defensiveness, and the inward thinking simply had to be banished before a whole new culture could be born. Many organisations had started down the road of outcome-based commissioning, but very few ever achieved promising results. It needed a lot of faith and persuasion that things would be different this time.

What made it work?

This section again reflects the transcript of the views of the team rather than the author. The team concluded that collaboration is a mindset not a process, that being open, receptive to ideas and feedback no matter how challenging and unpalatable, can be for the best. They created a System Optimisation Group, which gave real access to senior people not just for internal staff, but for service providers and service users too. Uncomfortable truths needed to be heard from the perspective of the source not filtered through management. It worked both ways. Some things cannot be changed; when everyone perceives the same obstacles they stop blaming and start problem-solving, facilitating systems thinking well beyond the current limits and hand-offs. A Creative Solutions Forum was set up to encourage creative partnerships and shared responsibility. Instead of asking for new resources, how could existing resources be better used? Where was the duplication? Where was the friction? What can we learn from each other and who has best practice to share? Could we buy services in wholly new ways? Blaming for failures achieves nothing, while learning from them achieves everything.

There needed to be some savings, but the service was enhanced rather than subjected to austerity measures. Barriers came down and complex needs were seen as complex rather than simplified to a label. Confidential data was shared once data protection became a discipline rather than a barrier. Morale improved. Shared endeavour and control replaced blame and defensiveness.

In conclusion, the culture was transformed because co-creation became a way of life not just a fuzzy term. Co-creation is most powerful when dealing with complex, intractable, and ambiguous challenges because, often it is the only way of solving them. Collaboration is a cornerstone of innovation. Bringing together diverse skills and viewpoints and rallying them behind a common cause is challenging, but if done well, the results can be startling as this case shows.

What can we learn?

Comparing these two cases, reveals obvious differences. First is the scale. Half a dozen people working in a relatively safe environment to create a new way of working is much less scary than social care covering a city. Second is legacy. Kaedim had a clean sheet, the last case needed a lot of undoing before new ways could really take root. For Kaedim, the knowledge behind the innovation was outside and needed to be recontextualised to embed it. In the social care case, most of the knowledge was within the organisation. The innovation catalyst was a process to facilitate its emergence and transformation into radically better ways of working. But there are also some significant common threads that weave through the whole of this paper.

Intersubjectivity

In all the examples including teaching, intersubjectivity played a vital role. Intersubjectivity goes beyond empathising with others, towards developing a common frame of reference as defined earlier. This shared perspective ensures that proposed innovation is *appropriate*, which will increase adoption. Doing the right thing is insufficient if beneficiaries do not perceive it that way. Without their buy-in, increased friction resists change stalling adoption (Simester, 2016). Our cases show that developing a common goal is a powerful technique to build intersubjectivity; achieving consensus was not a major obstacle. This should not be surprising, right at the top of Maslow's (1943) *Hierarchy of needs* is self-actualisation - a feeling that what we do makes a difference to others. This might explain growing beliefs that purpose driven organisations out-perform others, but empirical evidence is hard to find.

Intersubjectivity flies in the face of an economics orthodoxy that champions competition. Similarly, the doctrine of shareholder value argues that the purpose of a firm is to maximise returns to investors (Lazonick & O'Sullivan, 2000) which, by implication, sets investors in competi-

tion with the other stakeholders in the firm including customers.

This is illustrated below.

Profit v Purpose

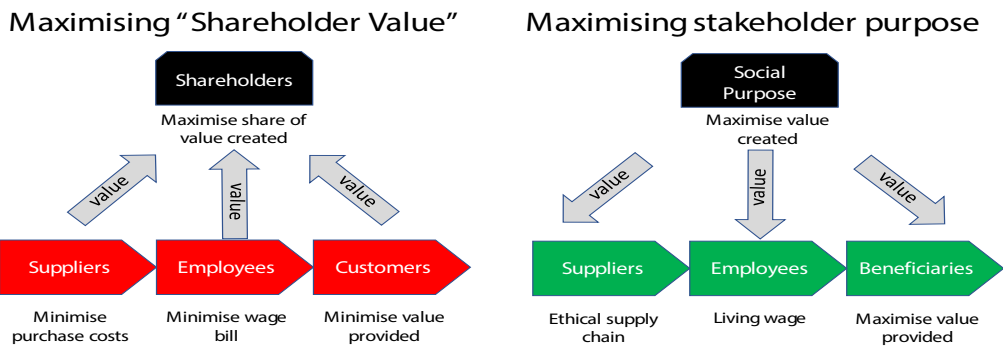


Figure 5: Profit v Purpose

Between these two extremes lie three other states defined in the table below and relating to factors that are explained in the text that follows.

Table 1:

The 5 levels of the Collaboration Pyramid

State	Definition	Degree of intersubjectivity
Co-creation	All 5 factors optimised	Maximum intersubjectivity
Collaboration	Some factors partially optimised	Pragmatic intersubjectivity
Cooperation	Competition tamed by rules	Interactions regulated
Co-existence	No interactions	
Competition	The object is to win	Negative intersubjectivity

If intersubjectivity is the key ingredient, what will improve its achievement? Below are five factors that the cases studied suggest are most important. They do overlap while remaining distinctive. These are illustrated in Figure 6 and further explained below.

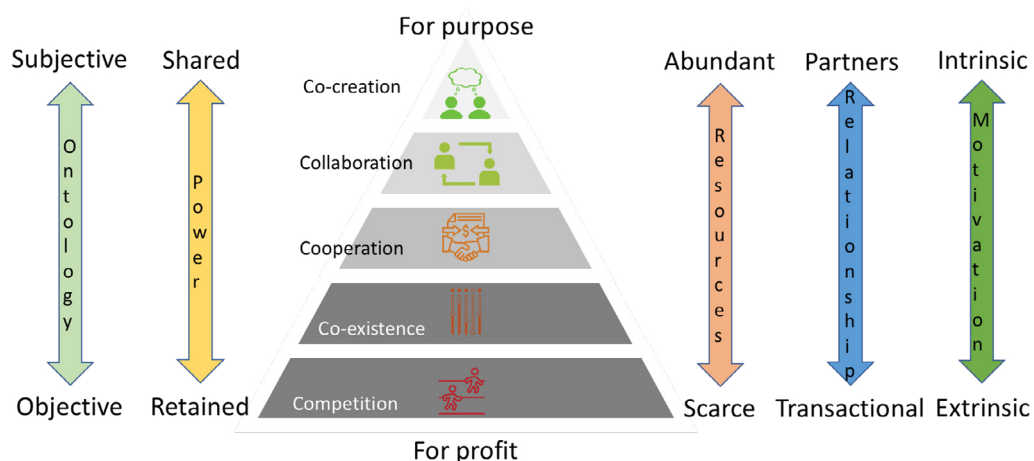


Figure 6 The collaboration pyramid

Power Symmetry

A key enabler of intersubjectivity in all the cases was hearing everyone's authentic voice. Questions posed by the powerful is 'innovation done for' rather than 'innovation done with' distinguishing collaboration from co-creation. It risks missing vital cues and undermining intersubjectivity. *Psychological safety* (Edmondson, 1999) and *conversational turn-taking* (Duhigg, 2016) have greater impact on team performance than individual member's capabilities, highlighting the importance of power symmetry in the modern workplace. This challenges those who have devoted their life to ascending the hierarchy as illustrated in the social care case study. Humble/servant leadership literature shows how good leaders overcome it.

The design literature debates whether innovation should be 'done for' or 'done with'. Some argue that customers do not know what they want according to (Norman & Verganti, 2014) and Apple cofounder Steve Jobs (Isaacson, 2011). Kaedim and leggings cases show customers know what outcome they seek but cannot conceive it until they see it. Intersubjectivity renders pent-up desire visible among customers to design a solution that intuitively addresses the gap. This has implications for participatory research methods and particularly the next thread.

Ontology

Objective ontology has huge appeal. Its reductionist generalisability is far simpler than messy reality, but is a poor predictor of what happens in the real world (Cole, 1996; Simon, 1996). If we accept that success is measured by the degree to which people adopt innovators' new ways of working, then motivation towards change must be a key unit of analysis. In the case of Kaedim, intersubjectivity took the form of understanding which use case would entice Aardman to commit resources. Not the obvious and objectively rational one - their main business. They had most to gain from their main line of business, but also the most risk. Key to gaining trust and support is an acceptance that individual's perceptions and behaviours are predictable only through the lens of their own context and environment (Simon, 1996). For the social care case, the task was even harder. Few commissioners or senior provider staff had experienced life as a *service user*. This widened the mismatch between what the users really wanted and providers' priorities. It is easy to conflate power symmetry with ontology. Power symmetry involves seeking users' opinions while ontology informs knowing how to ask. Collaboration is seeking user opinions through surveys and feedback questionnaires. Co-creation requires far less structured data collection methods empowering all parties to contribute to the questions as well as the answers. Conventional wisdom in lean start-up (Ries, 2011) urges validating hypotheses to determine whether a product fits the market need. As shown by the leggings, users may reject valuable radical innovation because the value is inconceivable. Constructionist approaches enable new knowledge emergence that nobody predicted, but everybody accepts. A power symmetry perspective argues that user buy-in prompts acceptance. An ontological perspective argues that acceptance comes from a culturally appropriate solution. In the social care case, both played a role, but without dialogue, the right opportunities may never have emerged. We may conclude that good practice in innovation research is to focus on insight discovery by prompting answers to questions that may not be obvious to ask.

Abundance

'Abundance mindset', first popularised by (Covey, 1989) believes that collaboration is more sustainable than competition. Empirical evidence supporting Covey's proposition is as thin as support for current economic orthodoxy (Stewart, 2009). Legitimacy for competition comes from the *invisible hand* (Smith, 1776), overlooking Smith's fuller call for regulation of *rentiers* and others gaining excess profit through power. Abundance believes that, despite the odds, innovation is worth trying to improve things and looks beyond constraints by reframing problems or employs outcome thinking about **what** good looks like before worrying about the **how**. A 'what' worth having, makes the 'how' more likely to be found. Kaedim demonstrated these behaviours

in tackling the challenge of using machine learning to automate animation. Solving it was very difficult, but that was not going to stop them.

For the social care case, considering collaboration a mindset rather than a process demonstrated abundance. It also highlighted that competition caused difficulties in service delivery that collaboration was likely to overcome creating better patient outcomes. Working together can bring a positivity that provides the grit and resilience needed to overcome hurdles to changing behaviour, bringing us to the fourth thread.

Partnering

Recent research in leadership explores the role of relations within teams (Uhl-Bien, 2006; Ospina, 2012). Sociocultural theory explains how relationships reveal differences in perspectives between parties and its implications for radical innovation. Relationships lie along a continuum from transactional (*entitative*) to partnering (*relational*) (Uhl-Bien, 2006). Transactional parties exchange information and assets in a detached way. Relational parties contribute to something larger than themselves similar in concept to *co-constructed mind*. Had Kaedim operated at arms-length to train its machine learning algorithms, they would be less likely to fit existing ways of working and be immediately useful. Partnership started by exploring a mutually beneficial outcome and continued by guiding progress towards it, delivering a solution that served their mutual purpose well.

The group innovating social care was far larger. Innovation emerged through synchronous co-created effort involving continuous input and discussion. This contrasts sharply with more typical transactional arrangements where innovators request information, receive it, and decide how to incorporate it, possibly including later previews anticipating minimal further input. Both forms have been described as collaboration, but the relative ability of the former to incorporate the emerging perspectives and concerns of different participants compared with the latter should be clear. Innovation is particularly difficult where procurement relationships are concerned as the social care case described. Commissioners are conditioned to think that competition is the driver of value for money. Rules about 'level playing fields' get in the way of intersubjectivity resulting in Government procuring tired (sic) and tested services from 'the usual suspects' rather than looking to innovation partnerships for additional value creation (Neild, 2021).

Motivation

That motivation is a clear mediator in adopting new ways of working stemmed from our first thought experiment. Recent studies suggest that *extrinsic* motivation powered by external inducement is weaker than inherently satisfying *intrinsic* motivation (Kuvaas, 2018). Neither case was motivated by inducements offered either way. People participated voluntarily, seeing the future benefits of getting the 'product' right. Willingness to participate in new services design indicates people perceive that these services matter and that they desire their existence. Persuading people to share personal insights that can only be obtained through dialogue is a big ask. People only agree if motivated towards the outcome. Extrinsic motivation masks this. If the only reason people participate is for the reward and feel no stake or interest in the outcome, then this not only risks introducing false data into the research process, but also gives little indication of likely future engagement.

Individual motivators need not be the same. Kaedim, saw value working with Aardman to confer legitimacy as well as access data and expertise to develop a product useful to animators. Aardman saw value in risk reduction. An effective product laid the foundation for future use cases, but failure would cost Aardman very little beyond time and effort. Social care patients sought better care that delivered individual benefits. Care providers felt *the system* getting in the way of good care provided motivation to change things. It is not just about income – social care is hardly the best remunerated occupation. These key drivers can only be discovered through

intersubjectivity - an outcome that all parties seek even if for different reasons. Kaedim were not after money from Aardman. If they were, they probably would not have achieved the results they did. Care providers were willing to give up income where others provided a better service for the greater good. Co-creation looks to intersubjectivity to surface the intrinsic motivation for change, a stronger force than carrot and stick (Kuvaas, 2018).

Conclusion

This paper opened with a paradox: why are the rewards of innovation so tantalising, yet the route to achieving them so obscure? Enroute, this paper explored the mediating role of culture and how it is both the problem and the solution for innovation. Culture's very invisibility is problematic because the outward and visible features that we use every day to distinguish between people shed so little light on their inner perception. Culture and previous experiences leave a mark on people that is both powerful and invisible.

Fortunately, educational psychologists and anthropologists researching cultural mediation have laid bare the communication gap opened by the unique way individual experiences lead us to process information. We have explored together through shared experiences such as driving, how the habit (Duhigg, 2012) part of our brains does the heavy lifting, freeing up capacity to dwell on more interesting topics. But we have also seen how hard habits are to break and mislead us when we experience the unexpected, helping explain why we find innovation so difficult.

Help is at hand. Multi-disciplinary teamwork unshackles us from the prisons of our habits. Whether relating others' experiences to our own or through distributed thinking, new and exciting possibilities emerge. These we can shape to lose their strangeness and gain acceptance by our habits, empowering us to do things better (incremental) or do better things (radical).

Unfortunately, this process is unconventional. To achieve great things, we need to rise above orthodoxy, embrace intersubjectivity and co-create then embody fresh meanings into better ways of working. Future iterations of this research develop aspects of this approach including the interplay between divergent (escaping situatedness) and convergent (ensuring appropriateness) modes of thinking and propose a new theory of motivated markets.

Biography

Mark was for 12 years an innovation and transformation consultant with a top tier consulting firm before starting his own business helping SMEs get more from their resources. His doctoral studies are the culmination of a long quest to understand why innovation so often fails to achieve its objectives.

Bibliography

- Bargh, J., & Morsella, E. (2008). *The Unconscious Mind* (Vol. 3) in Perspectives on Psychological Science pp73-79
- Bason, C. (2022). *Leading Public Sector Innovation (Second Edition): Co-creating for a Better Society*. Bristol University Press.
- Bereiter, C. (1985). Toward a Solution to the Learning Paradox. In M. Cole, *Cultural Psychology: a once and future discipline* (pp. 201-26).
- Bereiter, C. (1997). Situated Cognition and How to Overcome it. In J. Whitson, & D. Kirschner, *Situated Cognition: Social, Semiotic and Psychological Perspectives*.
- Blank, S. (2019, September r-October). Why companies do 'Innovation Theater' instead of actual innovation. *Harvard Business Review*,.
- Bourdieu, P. (1977). *Outline of a theory of practice*. (T. b. Nice, Ed.) Cambridge University Press.
- Bryson, A., Dale-Olsen, H., & Barth, E. (2009). *How Does Innovation Affect Worker Well-being?* Retrieved

from CEPD Discussion Paper: <http://eprints.lse.ac.uk/27781/>

- Carney, M. (2020). *The Reith Lectures, 2020: Mark Carney - How We Get What We Value, From Moral to Market Sentiments*. (M. Carney, Performer) BBC Radio 4. Retrieved from <https://www.bbc.co.uk/programmes/m000py8t>
- Christensen, C., Hall, T., Dillon, K., & David, D. (2016, September). Know Your Customers' "Jobs to Be Done". *Harvard Business Review*.
- Cole, M. (1996). *Cultural psychology : a once and future discipline*. Belknap Press of Harvard University Press.
- Cole, M., & Wertsch, J. (1996). Beyond the Individual-Social Antimony in Discussions of Piaget and Vygotsky. *Human Development*, 39, 250-256.
- Covey, S. (1989). *The seven habits of highly effective people: restoring the character ethic*. New York: Simon and Schuster
- Daniels, H. (2016). *Vygotsky and Pedagogy*. Oxford University Press.
- Duhigg, C. (2012). *The power of habit : why we do what we do in life and business*. Random House.
- Duhigg, C. (2016). *Faster Smarter Better The Secrets of Being Productive*. London: Random House.
- Edmondson, A. (1999). Psychological Safety and Learning Behavior in Work Teams. *Administrative Science Quarterly*, 350-383.
- Harari, D. (2020). *Productivity: Key Economic Indicators*. House of Commons Library. URL <https://commonslibrary.parliament.uk/research-briefings/sn02791/>
- Harris, M., & Albury, D. (2009). THE INNOVATION IMPERATIVE WHY RADICAL INNOVATION IS NEEDED TO REINVENT PUBLIC SERVICES FOR THE RECESSION AND BEYOND. Retrieved from www.nestalab.org.uk
- Isaacson, W. (2011). *Steve Jobs*. Simon and Schuster.
- Kaedim. (2020, 5). *Interview with the founders of Kaedim by Mark Neild*.
- Kempster, S., & Iszatt-White, M. (2013). Towards co-constructed coaching: Exploring the integration of coaching and co-constructed autoethnography in leadership development. *Management Learning*, 44(4), 319-336.
- Kuvaas, B. (2018). The Relative Efficiency of Extrinsic and Intrinsic Motivation. In A. Sasson, *At the forefront, Looking Ahead: Research-Based Answers to Contemporary Uncertainties of Management* (pp. 198-213). Universitetsforlaget.
- Lave, J., & Wenger, E. (1991). *Situated Learning Legitimate peripheral participation*. Cambridge University Press.
- Lazonick, W., & O'Sullivan, M. (2000). Maximizing shareholder value: a new ideology for corporate governance. *Economy and Society*, 29(1), 13-35.
- Lemke, J. (1997). Cognition, Context and Learning: a social semiotic perspective. In *Situated Cognition Theory: Social, Neurological and Semiotic Perspectives*.
- Magdis, S., Zorfas, A., & Leemon, D. (2015). The New Science of Customer Emotions. *Harvard Business Review*, 66-68.
- Martin, R. (2019). The High Price of Efficiency. *Harvard Business Review*.
- Maslow, A. (1943). A Theory of Human Motivation. *Psychological Review*.
- Moore, G. (2014). *Crossing the Chasm, 3rd Edition: Marketing and Selling Disruptive Products to Mainstream Customers*. Harper Collins.
- Moran, S. (2009). *Metaphor Foundations in Creativity Research: Boundary vs. Organism*. Retrieved from <https://onlinelibrary.wiley.com/doi/full/10.1002/j.2162-6057.2009.tb01303.x>
- Neild, M. (2017). *Innovate Your way to Extraordinary*. Kindle Direct Publishing
- Neild, M. (2021). *Why 'transforming procurement' won't transform procurement*. Retrieved from Transforming Society: <https://www.transformingsociety.co.uk/2021/03/04/why-transforming-procurement-wont-transform-procurement-with-social-value/>

- Neild, M., & Seymour, X. (2021). From Inconceivable to Obvious. *Research Without Borders*. University of Bristol. Retrieved from <https://www.youtube.com/watch?v=sWQi94z6D4E>
- Norman, D., & Verganti, R. (2014). Incremental and radical innovation: Design research vs. technology and meaning change. *Design Issues*, 30(1), 78-96.
- OECD (2015) *The Innovation Imperative*. OECD. Retrieved from https://www.oecd-ilibrary.org/science-and-technology/the-innovation-imperative_9789264239814-en
- Ospina, S. M. (2012). Social change leadership as relational leadership. In M. U.-B. (Eds.), *Advancing relational leadership research: A dialogue among perspectives*.
- Polt, R. (1999). *Heidegger an introduction*. Cornell University Press.
- Popper, K. (1978). *Three Worlds*. Tanner Lecture on Human Values, University of Michigan
- Quartz, S. (1993). Neural networks, nativism, and the plausibility of constructivism. *Cognition*.
- Ries, E. (2011). *The Lean Startup: How Constant Innovation Creates Radically Successful Businesses*. Penguin.
- Sawyer, K. (2003). Emergence in Creativity and Development. In *Creativity and development* (pp. 12-60). Oxford University Press.
- Sawyer, K. (2012). *Explaining Creativity: The Science of Human Innovation* (2 ed.). Oxford University Press.
- Simester, D. (2016). Why Great New Products Fail. Retrieved from <https://sloanreview.mit.edu/article/why-great-new-products-fail/>
- Simon, H. (1996). *The Sciences of the Artificial Third edition*. MIT Press
- Smith, A. (1776). *The Wealth of Nations*. W Strahan and T Cadell, London
- Stewart, M. (2009). *The Management Myth: Why the "Experts" Keep Getting It Wrong*.
- Tett, G. (2021). *Anthro-Vision How Anthropology can explain business and life*. London: Random House.
- Theisens, H. (2021). *Lean six sigma black belt*. Lean Six Sigma Academy
- Tversky, A., & Kahneman, D. (2004). Judgment under uncertainty: Heuristics and biases.
- Uhl-Bien, M. (2006). Relational leadership theory: Exploring the social processes of leadership and organizing. *The leadership quarterly*, 654-676.
- Ulwick, A. (1996). *Jobs to be Done*. Published online at: <https://jobs-to-be-done-book>
- Vygotsky, L. (1978). *Mind in society: The development of higher psychological Functions*. (M. Cole, V. John-Steiner, S. Scribner, & E. Souberman, Eds.) Harvard University Press.
- Vygotsky, L. (1987). Thinking and Speech. In *The Collected Works of L S Vygotsky, Volume 1*.
- Vygotsky, L., & Luria, A. (1930). *Studies on the History of Behaviour, Ape, Primitive and Child*.
- Wertsch, J. (1985). The Semiotic Mediation of Mental Life: L S. Vygotsky and M. M. Bakhtin. In E. Mertz, & R. Parmentier, *Semiotic Mediation Sociocultural and Psychological Perspectives*. Academic Press.
- Wertsch, J. (1985). *Vygotsky and the Social Formation of Mind*. Harvard University Press.
- Wilson, S., Davison, N., Clarke, M., & Casebourne, J. (2015). *Joining up public services around local, citizen needs Perennial challenges and insights on how to tackle them*.
- Young, E. (2018). Lifting the lid on the unconscious. *New Scientist*. Retrieved from <https://www.newscientist.com/article/mg23931880-400-lifting-the-lid-on-the-unconscious/>

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RESEARCH ARTICLE

Family language policy among Libyan families in the UK: maintaining heritage language in the home

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Abstract

This study explores Libyan families' language policy regarding the maintenance of Arabic heritage language by employing Spolsky's theoretical framework of the three interrelated components of language: ideology, practice, and management. Semi-structured interviews were used to collect data from seven bilingual Libyan families. The findings show that despite parents' positive attitudes towards Arabic language maintenance, Arabic is starting to lose ground in the home domain. There is also a mismatch between parents' language ideologies and their daily language practices and management indicating that positive attitudes are not always translated into language practices by those holding them.

Key words: Heritage language, language shift, family language policy, language ideology

Introduction

Most studies of heritage language maintenance and shift have taken place in Canada, USA, and Australia with regards to heritage languages such as Chinese, Spanish, Korean, Japanese (Cho, 2000; Curdt-Christiansen, 2009; Kwon, 2017; Stavans & Ashkenazi, 2022;) with little attention focused on Arabic heritage language among recent waves of immigrants such as Libyans in the UK. In this paper, immigrants refer to people who are foreign-born and immigrate from their home country (Liang, 2018) to study for a limited period, with the intention of returning to their place of departure (Jamai, 2008, p.53). Most Libyan immigrants came to the UK as students; they were sent by the Higher Ministry of Education to pursue Master studies or a

PHD. They intended to return to Libya after they finished their studies and work in the education sector to cover the shortage in local teachers. Unfortunately, after the 2011 revolution and the disintegration of Libya, these immigrants had to stay in the UK and apply for humanitarian asylum. They were eager to go back to Libya, but the current tough political situation and war in the country banned their return. They also desire to maintain their heritage language in the home, but they face an uphill battle to maintain it among their children (Brown, 2011, p. 32). How these immigrant families pass on their heritage language and culture to the next generation is the focal point of discussion in studies of heritage language maintenance and shift.

Heritage language (HL)

The term heritage language (HL) was first used in the Canadian context to refer to “a language other than one of the official languages of Canada that contributes to the linguistic heritage of Canada” (Park, 2013, p.31). This term gained popularity in the United States in the late 1990s and it was used to refer to minority languages (Montrul, 2015, p.13). Other common terms used to refer to a heritage language included *community, ethnic, minority, indigenous, immigrant, ancestral and non-official* language (Cummins, 2005; Fishman, 1991; Wiley & Valdés, 2000). Polinsky (2014) defines a heritage speaker as “one whose personal experience with the heritage language has led to some real amount of proficiency in that language” (p.1). In a similar vein, Montrul (2015) defines heritage speakers as individuals “of language minority groups who grow up exposed to their heritage language and the majority societal language” (p.16). In this view, the acquisition of the heritage language may begin before or concurrently with mastery of the dominant language, which in turn may lead to imbalanced bilingualism, often in favour of the dominant language (Kang & Yoon, 2021; Polinsky, 2014). However, some abilities in the heritage language may persist due to an early exposure to the language at home (Polinsky, 2014). While Polinsky’s definition emphasises the language competence of the heritage speaker, Cho’s (1997) definition focuses on ethnic identity. She defines heritage language as “the language associated with one’s cultural background and it may or may not be spoken in the home” (p.106). Similarly, Brown & Brown (2021) define heritage speakers as “individuals with familial or ancestral ties to the heritage language”. (p. 894). Furthermore, Potowski & Shin (2019) believe that heritage language is a part of one’s cultural heritage regardless of the person’s linguistic proficiency (p. 673). In fact, deciding who is a heritage language speaker is not simple and it has raised several issues in many articles (Brown & Brown, 2021; Montrul, 2010; Polinsky, 2014; Potowski & Shin, 2019).

Language shift (LS)

Language shift refers to a process whereby one language replaces another over generations (Smith-Christmas et al., 2019, p. 88). However, language shift is not simply an immediate replacement of one language by another, it is often a slow, gradual process (Seloni & Sarfati, 2013). This means that it may take one or more generations of users before a complete shift occurs (Pauwels, 2016, p.18). According to Spolsky (2012), the first generation tends to speak their native language while learning English (although they may alternate between languages), the second generation becomes bilingual whilst the third generation becomes monolingual in the dominant language with little, if any, knowledge in the first language (p.4). It is often in the second generation that language shift takes place due to the onset of school and the desire to blend into the new society (Montrul, 2011, p.157). Although parents may speak their native language to their children, their children respond in English, and they use it with their siblings and other children who share the same linguistic background (ibid). This shift leads to a generational gap in ethnic families, identity, and cultural loss along with language loss (Kit-Fong & Sae Oh, 2009, p.268). Although factors that lead to language shift are various and complex, previous research (Fishman, 1991; Pauwels, 2005) pointed to parents’ choice of the language at home: when parents do not speak their own native language with their children, that language is seriously threatened (Rindstedt & Aronsson, 2002, p.722).

Family Language Policy (henceforth FLP): A Theoretical framework

Family is considered an extremely critical domain for studying language policy because of its key role in shaping the child's linguistic environment (Schwartz, 2020). At the national level, language policy is a 'political decision' (Shen et al., 2021), whilst at the family level, it is an explicit and overt planning in relation to language use among family members (King et al., 2008, p. 907). Curdt-Christiansen & Huang (2020) have extended the notion of FLP to

encompass covert and implicit planning. Thus, family language policy is defined as explicit and overt as well as implicit and covert language planning in relation to language and literacy practices among family members (Curdt-Christiansen & Huang, 2020). Curdt-Christiansen's and Huang's definition has been criticised for lacking the emotional aspect related to family language policy. Tannenbaum (2012, p.58) argues that FLP seldom acknowledges the psychological dimensions such as love, hate, attraction, hopes, worries, close interactions, and aversion that are central in the analysis of home language policy. This implies considering family language policy as a 'form of coping or defence mechanism' that contributes to the family's emotional development and well-being.

Situated within the field of family language policy, this study adopts Spolskys' tripartite framework (2007, 2009) of language policy which is comprised of three interrelated components: language ideology, language practice and language management. Language practice is the "observable behaviours and choices – what people actually do" (Spolsky, 2007, p. 3) whilst language management is the explicit and observable effort by someone that has authority over the participants to modify their practices (Spolsky, 2009, p.4). Underpinning language practice and management strategies is language ideology, which refers to a "set of beliefs, attitudes, and norms that describes the value of a language and how it should be used" (Armstrong, 2014, p. 573). King (2013) considers language ideology as "the mediating link between language use and social organization" (p.5). It is generally regarded as the key driving force underlying the formation of any language policy (Curdt-Christiansen, 2014). Although family language policy is mainly invested in the home domain, recent research has highlighted the interplay between the family (described as micro domain) and the external (structural or macro) forces (Curdt-Christiansen, 2014; Lane, 2010; Mirvahedi, 2021; Selon & Safarti, 2013). Because the family is not close-knit, it is open to the influence of larger structural forces and institutions (King, 2013, p.50). Parents may resist, negotiate external forces, and show loyalty to their home language; they may also internalise them through their linguistic practices at home. To better understand heritage language maintenance and decline, this study conceptualises parents' language decisions and practice as embedded in a wider socio-political process.

Research Questions

This study aims to answer the following three questions:

- 1-What language ideologies do Libyan parents hold about Arabic heritage language?
- 2-What languages do they use with their children at home?
- 3-What language management strategies do they employ to maintain or reduce Arabic use among their children?

The study

Research design

This study is underpinned by an interpretive theoretical framework which places emphasis on understanding the social world from a subjective point. The interpretivist researcher believes that reality is subjective, context based, multi-layered and socially constructed (Guba & Lincoln,

1994, p.110). Every family in the study offered multiple interpretations and constructions of their home language policy through mutual interaction with the researcher once the desired rapport was established. The construction of participants' social reality was strongly influenced by multiple factors such as cultural factors (religion and identity) and broader socio-political factors such as public education. The researcher discovered this reality from families' perspectives, their experiences, and backgrounds (Staller, 2015, p.3). All perspectives were presented, and the value of understanding was determined by the degree to which the interpretations fit and reflected the participants' views (Ponelis, 2015, p.538). As this study is informed by an interpretive orientation, the researcher has adopted an exploratory design to investigate an under-researched phenomenon in the immediate context and to provide different views and interpretations.

Participants

This study is a part of a PhD research project, investigating Libyan parents' language policy in terms of the maintenance of Arabic heritage language. The study recruited 28 participants who lived in different cities in the UK. However, the vast majority were recruited from Newcastle due to the prior relationship with some participants. In this paper, I will discuss seven participating mothers who were aged 34-47 years old. The reason for selecting seven participants is because the paper is constrained by time and word limit. Furthermore, the choice of mothers only is because they had enough time to take part in this study. This means that their spouses were not included due to their busy schedule. The participants were all born in Libya, and they had been living in the UK between 11-16 years. Four of them came to the UK as students while the other three came with their husbands who were doing higher studies in UK universities. All these participants are highly-educated. Four participants obtained high degrees from UK universities while three obtained their degrees from Libya. Five participants were stay-at-home mothers at the time of the study while two of them were working at the weekend at a Libyan heritage school in Newcastle. Moreover, five participants lived in Newcastle, one mother lived in Huddersfield and one resided in Wolverhampton. The children were 23 heritage speakers (13 girls and 11 boys), and they were aged 3-23 years old. Fourteen of these children were born in the UK, seven were born in Libya whilst two were born in Poland and Turkey respectively. As a Libyan, sharing cultural and linguistic background with my participants has facilitated their recruitment and helped establish rapport. Information about participants is presented in this Table 1.

Table 1. Demographic characteristic of participants

Name of participants	Level of education	Number of children	Length of stay in the UK
Samira	D i p l o m a (Level 6)	5	12 years
Zena	BS	3	11 years
Hana	MA	2	11 years
Nehal	PHD	4	16 years
Hind	MA	2	11 years
Salma	BL	4	13 years
Amal	MA	4	12 years

Data collection methods

Being an interpretivist researcher, I adopted semi-structured interviews and participant observation as the main tools of data collection in this study to understand the meanings participants have constructed about their world, their lived experience, and their interpretations. Interviews were carried out with parents without the presence of their children because parents are the main social actors in heritage language maintenance or loss at home. Children, however, were included in the observations to explore their language use with their parents and other family members. The aims of the study were presented to participants precisely: the researcher gave detailed information about the nature of the study and how it would be conducted. Participants asked some questions about their roles in the study, and they were answered clearly. Additionally, they were assured about anonymity and confidentiality, and they were given pseudonyms. All interviews were conducted by phone and recorded using a high-quality device. Each interview lasted for an hour, sometimes more, depending on the information participants gave. Beside interviews, home observations were conducted with five Libyan families to explore their actual language practice and management at home. One family resided in Bristol and the other four families resided in Newcastle. Every family was observed once a week based on their availability and time. Field notes and audio recordings were used to supplement observations and to capture real data. All interview and observational data were transcribed verbatim from Arabic to English and coded using MAXQDA 2022 Software. In this paper, I will only focus on interview data and leave out observations because the participants cited were not observed.

Data analysis

Thematic Analysis (TA) was adopted as the main method to analyse qualitative data guided by Braun and Clarke's analytical approach (2006). TA was guided by the theoretical framework of this study which provided a detailed analysis of each family's language policy and management. All data were translated from Arabic to English and transcribed verbatim, transcriptions were reread multiple times to jot down initial ideas and to summarise what was said in the text. Then transcription was coded line-by-line using MAXQDA 2022 Software. Once codes were identified, they were combined with other similar codes to produce themes and then named clearly. The transcription and coding process started as soon as data were collected to get closer to the data and to familiarise myself with emerging issues (Charmaz, 2006).

Reflexivity

Because data analysis and interpretations are filtered through the researcher's personal lens, reflexivity about the researcher's own beliefs and assumptions is important (Salkind, 2012, p.4). Being Libyan myself and knowing some participants prior to conducting the study might have had an influence on their responses. Participants may have feared researcher's judgment and criticism because they failed to transmit Arabic language to their children. The topic of heritage language maintenance and shift is sensitive to those whose heritage language is strongly tied to religion as in the case of this study. Some Libyan parents felt guilty for not passing on Arabic language to their children because it is the language of AL Qur'an AL Kareem and prayers. They felt embarrassed when they were asked questions about language use at home and the efforts that they make to promote Arabic among their children. In fact, I also felt embarrassed to dig too deep. To reduce my influence, I explained to the participants that keeping heritage language is not an easy task because children are schooled in English, and they live in an English environment. I also made it clear that the aim of this study was not to judge them, it was to investigate a social phenomenon that may help them to follow more successful strategies by looking at what the literature has suggested and what other families have done.

Results

I represent the findings based on Spolsky's theoretical framework of language ideology,

language practice and language management. I will explain what Libyan parents thought about Arabic language, their language practice, and the strategies, if any, they use to maintain or reduce Arabic language use among their children.

Language ideology

Language ideology includes speakers' attitudes and beliefs about their language use (Park, 2022). Attitudes towards heritage language are considered a major theme in the field of language maintenance and shift (Abdelhadi, 2017). Alshafi (2022) defines language attitudes as "the beliefs people hold about their own language and those spoken by others" (p. 1293). The following quotations illustrate parents' attitudes towards Arabic language:

Amal:

'Arabic is very important to me; it is the language of AL Quran and religion". I want my children to read AL Quran correctly and do their prayers". I have been teaching my children Arabic since we came to the UK.

Samira shared the same comment:

'Arabic is very important to maintain, I want to pass it on to my children because it is the language of AL Quran, and it is our mother tongue'.

Beside AL Quran, Hind wants to maintain Arabic language for ethnocultural reasons:

'Arabic is very important to me; it is important for us as Arabs and Muslims. I mean, we should speak Arabic to keep our identity'.

Furthermore, the desire to return to the home country in the future influenced parent's home language policy. Nehal said:

'Arabic is very important because it is our mother tongue, and it helps my children read and recite AL Qur'an. My children will need Arabic when they return to Libya so that they can communicate, work, and study'.

Nehal still aspires to return to her home country after spending 16 years in the UK. This necessitates the learning of Arabic language by her children to facilitate their communication with their relatives, secure a job and ensure school success. This indicates that family members' perception of social change shapes their language policy (Curdt-Christiansen, 2009; Lanza & Gomes, 2020).

In the above excerpts, participating parents shared positive attitudes towards Arabic language maintenance, they considered it a core value because it is linked to AL Quran AL Kareem and their ethnic identity. They mentioned various reasons to maintain Arabic language and one of the main reasons was that Arabic is the language of AL Qur'an. Other reasons included cultural identity and the possibility of returning to the home country in the future. Unsurprisingly, keeping Arabic for religious reasons was the most motivating factor for Arabic language maintenance because the parents are Muslims, and they read AL Quran and supplicate in Arabic. They also want their children to read AL Quran and do their prayers in Arabic. Furthermore, they wish their children to speak Arabic fluently so that they can work and study in their home country and that is the reason why most of them send their children to Libyan heritage weekend schools or employ private tutors. The use of the word 'very' deliberately highlights the positive value and importance parents attach to Arabic language in the UK. This finding is consistent with the findings of Dweik et al. (2014, p.93) who investigated language attitudes among the Muslim Arabs in Vancouver and found that all participants considered Arabic a beautiful language because it is the language of AL Quran AL Kareem, and it is the marker of their cultural identity. In addition to the above

favourable attitudes towards Arabic language maintenance, Zena shared a different view:

‘... I want my children to use English because it is an international language, and I want my children to be open to the world. When I look to myself now, a mother who speaks Arabic and lives in the UK. I mean, what I gained from Arabic, I didn’t gain anything. I cannot speak English or communicate with people. The world is open, and my children will live and study here, they are speaking English, and this is enough for me. As I came to the UK, I don’t want to burden my children to learn something that will not benefit them in the future, I believe that Arabic will be only needed for AL Qur’an recitation and prayers, and this is my view.

The above excerpt expresses overt, negative attitudes towards Arabic language learning. Zena considered learning English important for her children’s academic success and that learning Arabic could interfere with their English proficiency. Her views implicitly reflect the asymmetrical linguistic hierarchy of languages in the UK and the societal beliefs about the functional value of minority languages. Because of the limited value of Arabic, she believed that her children will only need it to read AL Qur’an and do their prayers. She also considered speaking Arabic a problem, preventing her from communicating with people which had negative implications for Arabic maintenance at home. She decided not to burden her children with Arabic language so that they can focus on English only.

Language practice

As the name suggests, language practice is the ‘de facto language use at home’ (Spolsky, 2009). It is considered the ‘real’ language policy and the ‘most influential’ component (ibid). Some reasons accounting for speakers’ language choice include language proficiency, language preference, age, social status, education, the context of interaction, and the conversational interlocutor (Dumaing et al, 2013). In this study, all parents admitted the use of mixed languages at home. They used English to ensure their children’s academic success and to integrate themselves and their children into English society. The following quotations illustrate parents’ language practice:

Salma:

‘I was taking an English course at the college, and I was speaking English with my son. This was when I first came to the UK. I was so happy that my son spoke English fluently up to the point when I realized that he cannot speak Arabic at all. My husband was also speaking English with him (her son). When we visited Libya, he could not communicate with his relatives, and I was around him wherever he goes to translate to him. Thus, I started to use Arabic with him at home’.

Amal:

‘I use mixed languages at home, and I used this practice when I first came to the UK. When I first came, I did not speak English and I wanted to learn it and I wanted my children to learn it too. To learn English, I shared some English stories and books with my children, and we listened to English words and song. We wrote all the new words down in a notebook and we watched English channels and programmes. Furthermore, I asked my old children to teach their sister English because she was going to start school. You know, if you want to speak English, you need to practise’.

Salma and Amal adopted language as a problem orientation which aims at cultural assimilation and mainstreaming (Ruiz, 1984). They believed that Arabic should be eliminated while they were learning English (Zhang & Slaughter-Defoe, 2009). The need to master English was obvious as soon as they stepped in the UK because if they did not speak English, they would feel

isolated and held back. Therefore, they decided to speak and practise English with their children so that they could integrate well into British society and get access to public and educational services. After they learnt English, Salma realized that her home language policy had led to her son's difficulty in interacting with his relatives in the home country. Therefore, she adopted a new language policy that emphasised on Arabic language to suit her son's new linguistic needs.

Samira said

'I use Arabic at home, and I also use English namely with my young daughter because she had a language delay. My husband uses mixed languages too, but he uses English more than Arabic with his children. When his children talk to him in English, he responds in English automatically. He used Arabic for a while, then he adopted his children's English use'.

In this narrative, Samira mainly spoke English with her young daughter, believing that using both languages at home caused language delay. Her beliefs are exacerbated by the myth that providing HL input would inhibit the learning of the dominant language that is necessary for school success (Nakamura, 2016). Not only Samira spoke English at home, but also her husband adopted English as the default language in familial interactions. He was requested to shift from Arabic to English (Gafaranga, 2010) and he was socialised into the majority language use (Revis, 2019). While Fishman (1991) describes the family as 'a bulwark of language maintenance and reversing language shift', this bulwark has collapsed against the noxious influence of English in these families.

In the same vein, Hind and Hana used English to prepare their children for school:

Hind:

'I use mixed languages with my children, and I started to mix the languages since they were younger. I did not expect that my children will reach the point where they speak English only. I used English because my children started their school, and I wanted them to adjust to the majority language. For example, before my son joined nursery, I taught him English words instead of Arabic so that he does not get shocked in the school, and he communicates with his teachers and peers. From thereon, he started to speak English only and now I find it difficult to teach him Arabic'.

Hana:

'I started to use English with my children when they started their nursery. I explained to them in English, and I talked with them in English. After they spoke English, I switched back to Arabic, but I still alternate between Arabic and English at home'.

The language policy in England still privileges English despite the multilingual population (Kirsch, 2012). This means that Libyan children who enter the education system should learn English quickly or fail. Accordingly, the above parents used English deliberately instead of Arabic to help their children adjust to an English environment. By raising their children in English, they guaranteed that they will not fall behind at school and they will have better and easier communication with their teachers and peers. They believed that exposing their children to Arabic input would minimise English learning while children's exposure to English at school is so powerful that parent's efforts are not needed to enhance language development (Nakamura, 2016).

Language management

As mentioned above, language management refers to the strategies parents use to shape their children's linguistic behaviour (Spolsky, 2009, p.4). In this study, parents employed monolingual discourse language strategies such as parallel strategy and minimal grasp strategy. Parallel

discourse strategy means parents use the heritage language with their children while their children use the majority language (Gafaranga, 2010). Minimal grasp strategy is showing non-understanding to the children's English utterance (Lanza & Gomes, 2020). For example,

Nehal stated:

'When they (her children) use English with me, I sometimes use Arabic to encourage them to use it. I tell them that if they want me to do something for them, they should use Arabic without mistakes. They try to speak Arabic, but they struggle, and they find it difficult. Hence, they resist my language policy and continue in English because they feel more comfortable with it'.

Nehal adopted parallel discourse strategy when her children resisted her language policy (she maintained the conversation in Arabic while her children used English). The use of this strategy did not encourage her children to produce Arabic utterances and it developed non-reciprocal interaction. This strategy also led to dual-lingual interaction in which either language was permissible. Dual-lingual interaction refers to the use of different languages by speakers in the same conversation (Nakamura, 2018, p. 185). In addition to the use of parallel strategy, two parents used minimal grasp language strategy (pretending non-understanding) when their children addressed them in English.

Amal stated:

'When my children speak English, I pretend non-understanding and I say to them: what did you say? I did not quite understand you'. They try to speak Arabic, but they feel that they are forced to speak it. In fact, they prefer to speak English because it easier for them than Arabic'.

Likewise, Zena said:

'I show non-understanding to my children so that they speak Arabic, but they do not accept this strategy easily because their first language is English, and their second language is Arabic'.

Apparently, parents used this strategy to constrain their children's language choice and negotiate a monolingual context of interaction. The children reacted negatively to this strategy, and they rejected it. They did not feel that they are obliged to speak Arabic with their parents since they understand English.

Additionally, Hind stated:

'I do not follow any language policy at home, when my son talks about an interesting topic, I do not like to interrupt him or ask him to speak Arabic. I let him continue his conversation, I encourage him, and I respond to him in English too'.

Even if Hind said that she does not follow any language policy at home, she used no-reaction policy. She did not react to her child's English use because she did not want to interrupt his conversational flow and shift the conversation to Arabic teaching practice. Moreover, she adopted a monolingual interaction by speaking English with her son, thus sending him an implicit message that speaking English is acceptable at home. As a result, her son has developed receptive language skills which means that he can understand Arabic, but he cannot produce it (Polinsky, 2018).

Hana shared the same views:

'I used to follow some steps in the past such as 'I don't respond to my children when they use English with me, but I found these steps useless now and I allow them to use English'.

Interviewer: why?

Hana:

‘Because they do not understand Arabic, and they do not even know how to use it’.

Though Hana employed some sanction strategies such as not responding when her children addressed her in English, she believed that her language practice does not have the power to alter her children’s current linguistic behaviour. This is expressed by De Houwer (1999, p.83) as weak impact beliefs which refer to ‘the degree to which parents see themselves incapable of changing their children’s language’. Since her children are not able to speak Arabic very well, she gave it up and accepted the use of English at home.

Parents’ involvement and home literacy practice

Beside the use of discourse language strategies, parents commented on their involvement in home literacy practices as part of Arabic language management strategies. Home literacy practices and parental involvement include joint book reading, explicit language teaching, homework help, cultural and ritual practices, and the use of educational devices (educational games, educational TV programmes, computer games, and storybooks) (Curdt-Christiansen & La Morgia , 2018; Schwartz, 2020;). For instance,

Nehal shared:

‘I do not teach my children Arabic at home; I do not even have any Arabic learning resources. The only resources I have are Libyan weekend school and TV. I sometimes switch TV on Arabic channels and I ask my children to watch them instead of spending great time on their phones. In fact, my children are not interested in anything related to Arabic learning’.

Zena said:

‘I have not taught my children Arabic at home; I left it to the school and the mosque because they will not accept it from me. They do not accept Arabic easily’.

Samira shared the same views as Zena:

‘Frankly, I do not make any efforts regarding Arabic language maintenance at home. The only thing I do is showing non-understanding to my children when they use English with me’.

Salma:

‘I used to bring Majed (Arabic cartoon) magazines from Libya and my husband sometimes brings some Arabic stories from London. I sometimes read these magazines with my daughter because she loves reading’.

In these excerpts, parents provided few resources for Arabic language learning, and they were less engaged in home literacy practices. They claimed that Arabic resources are not available in the UK and their children are not interested in anything related to Arabic learning. In addition, they believed that teaching Arabic is the school’s responsibility, rejecting their role in teaching it and in creating possibilities for promoting additive bilingualism. Such limited involvement could be attributed to the challenges parents encounter to keep up with school demands which leaves no time or energy for Arabic language development.

Discussion and conclusion

The aim of this study is to explore whether Arabic Language is maintained, learned, or even lost from a family language policy perspective. Overall, all parents except one attached great importance to Arabic language maintenance and they wanted to transmit it to their children. They saw Arabic as a core value linked with (Smolicz, 1981) other core values such as religion and identity. The desire to return to the home country in the future was also a strong factor informing parents' home language decision. Parents want to maintain Arabic so that their children can join schools in the home country and find jobs. By situating FLP within a larger socio-political setting, the analysed data showed that Arabic language is starting to lose status in the home domain. The implementation of FLP was highly influenced by sociocultural factors and the broader educational system in the UK. Parents decided to promote and support English for their children because it is the language of education and social mobility. This act of agency reflects their aspirations for their children's academic success and future development. If agency means the capacity to act and change (Curdt-Christiansen & Wang, 2018), Libyan parents' acts conform with the societal ideology about the position and different functions of the two languages (English and Arabic). This reveals parents' weak agency in resisting and negotiating the broader socio-political forces. Apart from language ideologies, parents alternated between Arabic and English or used English only to ensure their children's academic success and to enable them to blend well into British society. They accommodated their children's language choice and behaved like 'linguistic hybrids' (Kirsch, 2012). The adoption of this language practice at home provided children with more exposure to English and facilitated its learning. It also gave children a clear message that it was alright to speak English with parents who were able to understand it (Kasuya, 1998). As parents are the main source of Arabic input, the frequent use of English has developed receptive skills in their children, and it has affected the input that their children need in Arabic. While parents cherished their Arabic language, they acted otherwise. In other words, they showed a clash between what they reported and what they actually used at home. This is consistent with the findings of Mirvahedi & Jafari (2021) who explored language practice among Azerbaijani-Farsi bilingual families in Zanjan, Iran. They found out that parents promoted Farsi at home although they expressed strong attachment to Azerbaijani, their heritage language (p.16). In terms of language management, parents employed a limited range of language discourse strategies such as parallel discourse strategy and minimal grasp strategy. The use of these strategies did not influence their children to speak Arabic at all and they led to dual-lingual interaction at home. In fact, children resisted their parents' language strategies for two reasons: they lacked Arabic language proficiency, and they were aware of their parents' English competence. Children often do not use their first language when they are aware that their interlocutor can speak English (Pauwels, 2005, p.126). Looking at parent's involvement in home language activities, it shows that parents provided limited language literacy resources and they were less engaged in home literacy practices. The only resources they have are TV and Libyan weekend school along with a few books or magazines. By these actions, they revealed a sense of weak responsibility for providing the linguistic environment and context for literacy development (Curdt-Christiansen & Wang, 2018). To conclude, this study attempts to contribute to the existing research in the field of FLP by investigating a minority that has been rarely investigated in the previous studies. Importantly, it explores the interaction between parents' language policy and the societal ideologies of the country. It is hoped that this study will trigger further research on Arabic heritage language in the UK context with a specific focus on immigrants and refugees.

References

- Abdelhadi, M. (2017). *Language maintenance factors: Reflections on the Arabic language*. In *3rd Asia Pacific Conference on Contemporary Research*. Kuala Lumpur, Malaysia.
- Alsahafi, M. (2022). When homeland remains a distant dream: language attitudes and heritage language maintenance among Rohingya refugees in Saudi Arabia. *International Journal of Bilingual Education and Bilingualism*, 25(4), 1292-1303.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*,

3(2), 77-101.

- Brown, C. L. (2011). Maintaining heritage language: Perspectives of Korean parents. *Multicultural education, 19*(1), 31-37.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Sage.
- Cho, G. (2000). The role of heritage language in social interactions and relationships: Reflections from a language minority group. *Bilingual research journal, 24*(4), 369-384.
- Cho, G., Cho, K. S., & Tse, L. (1997). Why ethnic minorities want to develop their heritage language: The case of Korean Americans. *Language, Culture and Curriculum, 10*(2), 106-112.
- Cummins, J. (2005). A proposal for action: Strategies for recognizing heritage language competence as a learning resource within the mainstream classroom. *Modern Language Journal, 585-592*.
- Curdt-Christiansen, X. L. (2009). Invisible and visible language planning: Ideological factors in the family language policy of Chinese immigrant families in Quebec. *Language policy, 8*(4), 351-375.
- Curdt-Christiansen, X. L. (2014). Planning for development or decline? Education policy for Chinese language in Singapore. *Critical Inquiry in Language Studies, 11*(1), 1–26. doi:10.1080/15427587.
- Curdt-Christiansen, X. L., & Huang, J. (2020). Factors influencing family language policy. *Handbook of social and affective factors in home language maintenance and development, 174-193*.
- Curdt-Christiansen, X. L., & La Morgia, F. (2018). Managing heritage language development: Opportunities and challenges for Chinese, Italian and Pakistani Urdu-speaking families in the UK. *Multilingua, 37*(2), 177-200.
- Curdt-Christiansen, X. L., & Wang, W. (2018). Parents as agents of multilingual education: Family language planning in China. *Language, Culture and Curriculum, 31*(3), 235-254.
- De Houwer, A. (1999). Environmental factors in early bilingual development: The role of parental beliefs and attitudes. *Bilingualism and migration, 1999, 75-96*.
- Dumanig, F. P., David, M. K., & Shanmuganathan, T. (2013). Language choice and language policies in Filipino-Malaysian families in multilingual Malaysia. *Journal of Multilingual and Multicultural Development, 34*(6), 582–596. doi:10.1080/01434632.2013.784323
- Dweik, B. S., Nofal, M. Y., & Qawasmeh, R. S. (2014). Language use and language attitudes among the Muslim Arabs of Vancouver/Canada: A sociolinguistic study. *International Journal of Linguistics and Communication, 2*(2), 75-99.
- Fishman, J. A. (1991). *Reversing language shift: Theoretical and empirical foundations of assistance to threatened languages* (Vol 76). Clevedon: Multilingual Matters.
- Gafaranga, J. (2010). Medium request: Talking language shift into being. *Language in Society, 39*(2), 241–270.
- Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. *Handbook of qualitative research, 2*(163-194), 105.
- Jamai, A. (2008). *Language use and maintenance among the Moroccan minority in Britain*. University of Salford (United Kingdom).
- Kang, H., & Yoon, J. (2021). Heritage Languages in Japan and Korea. In S. Montrul & M. Polinsky (Eds.), *The Cambridge Handbook of Heritage Languages and Linguistics* (*Cambridge Handbooks in Language and Linguistics*, pp. 111-128). Cambridge: Cambridge University Press. doi:10.1017/9781108766340.007
- Kasuya, H. (1998). Determinants of language choice in bilingual children: The role of input. *International Journal of Bilingualism, 2*(3), 327-346.
- King, K. A. (2013). A tale of three sisters: Language ideologies, identities, and negotiations in a bilingual, transnational family. *International Multilingual Research Journal, 7*(1), 49-65.
- King, K. A., Fogle, L., & Logan-Terry, A. (2008). Family language policy. *Language and linguistics com-*

pass, 2(5), 907-922.

- Kirsch, C. (2012). Ideologies, struggles and contradictions: An account of mothers raising their children bilingually in Luxembourgish and English in Great Britain. *International Journal of Bilingual Education and Bilingualism*, 15(1), 95-112.
- Kit-Fong Au, T., & Sae Oh, J. (2009). Korean as a heritage language. In P. Li (Author) & C. Lee, G. Simpson, & Y. Kim (Eds.), *The Handbook of East Asian Psycholinguistics* (pp. 268-275). Cambridge: Cambridge University Press. doi:10.1017/CBO9780511596865.021
- Kondo-Brown, K., & Brown, J. D. (Eds.). (2021). *Teaching Chinese, Japanese, and Korean heritage language students: Curriculum needs, materials, and assessment*. Routledge
- Kwon, J. (2017). Immigrant mothers' beliefs and transnational strategies for their children's heritage language maintenance. *Language and Education*, 31(6), 495-508.
- Lane, P. (2010). "We did what we thought was best for our children": A nexus analysis of language shift in a Kven community. *2010 (202)*, 63-78. <https://doi-org.uoelibrary.idm.oclc.org/10.1515/ijsl.2010.014>
- Lanza, E., & Gomes, R. L. (2020). Family language policy: Foundations, theoretical perspectives and critical approaches. *Handbook of Home Language Maintenance and Development*, 153-173.
- Liang, F. (2018). Parental Perceptions toward and Practices of Heritage Language Maintenance: Focusing on the United States and Canada. *Online Submission*, 12(2), 65-86.
- Mirvahedi, S. H. (2021). What can interactional sociolinguistics bring to the family language policy research table? The case of a Malay family in Singapore. *Journal of Multilingual and Multicultural Development*, 1-16.: A time for renewal. *Bilingual Research Journal*, 24(4), iii-vii.
- Mirvahedi, S. H., & Jafari, R. (2021). Family language policy in the City of Zanjan: a city for the forlorn Azerbaijani. *International Journal of Multilingualism*, 18(1), 1-23.
- Montrul, S. (2010). Current issues in heritage language acquisition. *Annual Review of Applied Linguistics*, 30, 3-23.
- Montrul, S. (2011). Introduction: The linguistic competence of heritage speakers. *Studies in Second Language Acquisition*, 33(2), 155-161
- Montrul, S. (2015). Heritage languages and heritage speakers. In *The Acquisition of Heritage Languages* (pp. 13-40). Cambridge: Cambridge University Press. doi:10.1017/CBO9781139030502.002
- Nakamura, J. (2016). Hidden bilingualism: Ideological influences on the language practices of multilingual migrant mothers in Japan. *International Multilingual Research Journal*, 10(4), 308-323.
- Nakamura, J. (2018). Parents' use of discourse strategies in dual-lingual interactions with receptive bilingual children. *Crosslinguistic research in monolingual and bilingual speech*, 181-200.
- Park, M. Y. (2022). Language ideologies, heritage language use, and identity construction among 1.5-generation Korean immigrants in New Zealand. *International Journal of Bilingual Education and Bilingualism*, 25(7), 2469-2481.
- Park, S. M. (2013). Immigrant students' heritage language and cultural identity maintenance in multilingual and multicultural societies. *Concordia Working Papers in Applied Linguistics*, 4, 30-53.
- Pauwels, A. (2005). Maintaining the community language in Australia: Challenges and roles for families. *International journal of bilingual education and bilingualism*, 8(2-3), 124-131.
- Pauwels, A. (2016). *Language maintenance and shift*. Cambridge University Press.
- Polinsky, M. (2014). *Heritage languages and their speakers: Looking ahead*.
- Polinsky, M. (2018). *Heritage languages and their speakers* (Vol. 159). Cambridge University Press.
- Ponelis, S. R. (2015). Using interpretive qualitative case studies for exploratory research in doctoral studies: A case of information systems research in small and medium enterprises. *International Journal of Doctoral Studies*, 10, 535.
- Potowski, K., & Shin, S. (2019). Heritage Language Instruction. *The Cambridge Handbook of Language*

- Learning (*Cambridge Handbooks in Language and Linguistics*, pp. 673-695). Cambridge: Cambridge University Press. doi:10.1017/9781108333603.029
- Revis, M. (2019). A Bourdieusian perspective on child agency in family language policy. *International Journal of Bilingual Education and Bilingualism*, 22(2), 177-191.
- Rindstedt, C., & Aronsson, K. (2002). Growing up monolingual in a bilingual community: The Quichua revitalization paradox. *Language in Society*, 31(5), 721-742.
- Ruiz, R. (1984). Orientations in language planning. *NABE journal*, 8 (2), 15-34.
- Salkind, N. J. (2012). *Encyclopaedia of research design* (Vols. 1-0). Thousand Oaks, CA: SAGE
- Schwartz, M. (2020). 10 Strategies and practices of home language maintenance. In *Handbook of Home Language Maintenance and Development* (pp. 194-217). De Gruyter Mouton.
- Seloni, L., & Sarfati, Y. (2013). (Trans) national language ideologies and family language practices: a life history inquiry of Judeo-Spanish in Turkey. *Language Policy*, 12(1), 7-26.
- Shen, Q., Wang, L., & Gao, X. (2021). An ecological approach to family language policy research: the case of Miao families in China, *Current Issues in Language Planning*, 22:4, 427-445, DOI: 10.1080/14664208.2020.1764730
- Smith-Christmas, C., Bergroth, M., & Bezicioğlu-Göktolga (2019). A Kind of Success Story: Family Language Policy in Three Different Sociopolitical Contexts. *International Multilingual Research Journal*, 13(2), 88-101. <https://doi.org/10.1080/19313152.2019.1565634>
- Smolicz, J. (1981). Core values and cultural identity. *Ethnic and racial studies*, 4(1), 75-90.
- Spolsky, B. (2007). Towards a theory of language policy. *Working Papers in Educational Linguistics (WPEL)*, 22(1), 1.
- Spolsky, B. (2009). *Language management*. Cambridge University Press.
- Spolsky, B. (2012). Family language policy—the critical domain. *Journal of Multilingual and Multicultural Development*, 33(1), 3-11.
- Staller, K. M. (2015). Qualitative analysis: The art of building bridging relationships. *Qualitative Social Work*, 14(2), 145-153.
- Stavans, A. (2012). Language policy and literacy practices in the family: the case of Ethiopian parental narrative input. *Journal of multilingual and multicultural development*, 33(1), 13-33.
- Stavans, A., & Ashkenazi, M. (2022). Heritage language maintenance and management across three generations: The case of Spanish-speakers in Israel. *International Journal of Bilingual Education and Bilingualism*, 25(3), 963-983.
- Tannenbaum, M. (2012) Family language policy as a form of coping or defence mechanism, *Journal of Multilingual and Multicultural Development*, 33:1, 57-66, DOI: 10.1080/01434632.2011.638074
- Wiley, T. G., & Valdés, G. (2000). Editors' introduction: Heritage language instruction in the United States: A time for renewal. *Building Research journal*, 24 (4), iii-vii
- Zhang, D., & Slaughter-Defoe, D. T. (2009). Language attitudes and heritage language maintenance among Chinese immigrant families in the USA. *Language, culture and curriculum*, 22(2), 77-93.

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