# UNIVERSITY OF BIRMINGHAM

## University of Birmingham Research at Birmingham

# The use of storytelling intervention for the promotion of physical activity in chronically ill patients

Bryne, Charlotte; Soundy, Andrew

DOI:

10.12968/ijtr.2019.0091

License:

None: All rights reserved

Document Version Peer reviewed version

Citation for published version (Harvard):

Bryne, C & Soundy, A 2020, 'The use of storytelling intervention for the promotion of physical activity in chronically ill patients: an integrative review', *International Journal of Therapy and Rehabilitation*, vol. 27, no. 8. https://doi.org/10.12968/ijtr.2019.0091

Link to publication on Research at Birmingham portal

Publisher Rights Statement:

This document is the Accepted Manuscript version of a Published Work that appeared in final form in International Journal of Therapy and Rehabilitation, copyright © MA Healthcare, after peer review and technical editing by the publisher. To access the final edited and published work see https://doi.org/10.12968/ijtr.2019.0091

**General rights** 

Unless a licence is specified above, all rights (including copyright and moral rights) in this document are retained by the authors and/or the copyright holders. The express permission of the copyright holder must be obtained for any use of this material other than for purposes permitted by law.

- •Users may freely distribute the URL that is used to identify this publication.
- •Users may download and/or print one copy of the publication from the University of Birmingham research portal for the purpose of private study or non-commercial research.
- •User may use extracts from the document in line with the concept of 'fair dealing' under the Copyright, Designs and Patents Act 1988 (?)
- •Users may not further distribute the material nor use it for the purposes of commercial gain.

Where a licence is displayed above, please note the terms and conditions of the licence govern your use of this document.

When citing, please reference the published version.

Take down policy

While the University of Birmingham exercises care and attention in making items available there are rare occasions when an item has been uploaded in error or has been deemed to be commercially or otherwise sensitive.

If you believe that this is the case for this document, please contact UBIRA@lists.bham.ac.uk providing details and we will remove access to the work immediately and investigate.

Download date: 10. Apr. 2024

Abstract

Aims

To develop an understanding of what a storytelling intervention entails, its main effects and how

this causes the promotion of physical activity in chronically ill patients.

Methods

An integrative review was undertaken in three stages; a) search b) appraisal c) synthesis. Studies

were included if they represented participants with a chronic illness and used a storytelling

approach for the intervention as well as including physical activity as a component of the

intervention.

Findings:

Fourteen articles were identified that included a total of 818 participants (191 male, 348 female, 279

unknown). No articles were identified as flawed and all were included in the synthesis. Four themes

were identified: (1) ideal processes within interventions, (2) psychosocial factors which influenced

storytelling, (3) perceived outcomes relating to storytelling. And (4) the perceived benefits of

physical activity.

Conclusions:

This review develops a deeper understanding of the required processes, associated factors and

outcomes of storytelling interventions for people with chronic illness. It provides evidence of how

storytelling can be used to promote physical activity. Further research into storytelling interventions

is required.

Key words: Storytelling; intervention; review; chronic illness; physical activity

**Key Points** 

1

- Individuals with chronic illness can benefit from storytellying interventions that focus on physical activity.
- Compared to a control condition (factual or didactic advice provided by experts')
   storytelling interventions appeared to enhance; (a) intrinsic motivation for behavior change
   (b) social identity of the participant and (c) self-regulation of behavior.
- Mechanisms which appeared to explain the positive benefits from storytelling included; (a)
  the use of language e.g., use of metaphors, (b) the creation of a trusted environment to share
  information and (c) opportunities for positive self-reflection which appeared to enhanced
  psychological adaptation.
- Peer comparison appeared as one social mechanism that could explain particular psychosocial and health benefits from across the storytelling interventions.
- Individuals perceived that physical activity as a part of the storytelling intervention was associated with several benefits including; (a) increased life satisfaction, quality of life, meaning and fulfillment and (b) a positive distraction from their own lives or stories.

#### **Reflective Questions**

- How are stories currently viewed or judged within the clinical setting where you work? Are people's stories categorised into a single word to describe a reaction or adaptation to what has happened to them? E.g., a health care professional may say 'that person is in denial or unrealistic'. What are the problems with this?
- When you listen to stories of suffering do you perceive a need to 'jump in' and fix the story from your perspective? If you do, could you first ask; (a) should there be a correct story to tell? (b) Does their story have to change right away? And (c) what have they found helps previously from their own experience?

 Can you ask participants if there are any peers or people with their condition that view life differently? Can you ask them to consider this further? Could they begin this by being an observer of peers through different platforms like internet blogs?

#### **Introduction**

Chronic illness physical activity and a need for behaviour change

A chronic illness is defined as, suffering from a disease which has no available cure, the diseases are typically progressive and are the leading cause of death and disability worldwide (World Health Organisation, 2019). Fifteen million people in the UK have a chronic condition (The Kings Fund, 2019). There is a strong focus recently on promoting self-management strategies as a way to live and cope with chronic illness. A main benefit of this is the enhancement of the autonomy of patients (National Health Service, 2014). Physical activity is regarded as an essential component of selfmanagement for people with chronic illness (e.g., Morey et al., 2008; Ellis et al., 2013). Benefits from physical activity on chronic illness are consistent and include psychological benefits on mental health (e.g., Stubbs et al., 2018) and physical benefits (e.g., Piercy and Troinao, 2018). One important factor that enhances the experience of physical activity is the group setting and ability to share with similar others (e.g., Chow, 2018; Hawkins et al., 2014; Nguyen et al., 2018). Research across chronic illness conditions has consistently highlighted the positive impact of group members who are interested in physical activity and can participate in listening and sharing with one another (e.g., Belza et al., 2004; Ley and Barrio, 2012; Soundy et al., 2019). One particular approach which uses a group environment successfully to positively influence change in physical activity intensions and behaviour is storytelling.

Storytelling as a tool for behaviour change

Storytelling is a unique and powerful tool that allows opportunity for the teller to reflect on one's actions and share this with others (Capecci and Cage, 2012). Storytelling contains different components including the narrative shared and the perspective given. Particular features (Lugmayr et al., 2017) often define the story such as the plot, time, expression of the teller's reality, the meaning within culture, group or particular environment, the impact of events, characters and details within the story as well as elements of interactivity focusing on purpose of the story such as engagement, flow and collaboration. It is often delivered through different mediums including written, digital, telephone and in person. Storytelling is a universal communication technique which enable people to express their reality, memories, hopes for the future and deepest feelings (Gucciardi et al., 2016). Within physical activity settings the stories can be positive and provide examples of health behaviour change that can be accessed by others (Soundy et al., 2019). The success of storytelling is likely due to the ability to relate to others stories who face similar challenges (Høybe et al., 2004).

#### Listening to stories

Our work suggests that a lack of 'narrative competence' by health care professionals can explain poor health care professional-patient interactions (Soundy et al., 2013). Narrative competence is concerned with the ability of a health care professional to listen and honour the stories shared by patients within clinical practice. Health care professionals are required to listen to stories because the story shared by people with chronic illness has hidden psychological meaning. This relates to the story plot revealing hope, psychological adaptation and emotional well-being (Soundy, 2018). However, a story may be silenced if it is perceived as 'unrealistic' for the context of rehabilitation (Soundy et al., 2010a) or if it categorised according to traditional models of psychological adaptation, using terms such as a person being 'in denial' (Soundy et al., 2010b). The limited judgement of stories results in reduced narrative competence. A health care professional who has narrative competence is more likely to act in ways that will support the patient's psychological

well-being (Charon, 2006) and is an essential communication skill that all HCPs should have. Storytelling interventions can enhance experiences of personalised care often because of the environment which is created and ability to share (Atkinson and Rubineli, 2012).

The benefits of physical activity storytelling interventions

Various studies across multiple chronic illnesses identify that storytelling can enhance the ability to cope with suffering and provide emotional comfort for the teller and those close to them (e.g., Akard et al., 2015; Soundy and Reid, 2019). Further to this the environment where stories are disclosed is often perceived as safe (Nurser et al., 2017) and the experience has been reported to aid a positive co-construction of collective and individual social identities (Hsieh, 2010; Nurser et al., 2017). Storytelling with a particular focus on physical activity can give people with chronic illness access to stories which can motivate behavioural change (e.g., Soundy et al., 2019). This is likely achieved by several mechanisms identified by different authors; (a) enhancing trust in peers, exercise confidence and intension to undertake physical activity (Falzon et al., 2014; Soundy et al., 2019), (b) positive social comparisons, an enhanced mind-set and a sense of hope for change (Soundy et al., 2019) and (c) an ability to take risks which establish new boundaries of physical possibility (Higgs and Soundy, 2020).

#### The need for further reviews

A limited number of systematic reviews have been written on this topic (Moreau et al., 2018; Schoenau and Jackson, 2016; Soundy and Reid, 2019; Gucciadi et al., 2016; Perrier and Ginis, 2016). Two reviews focus on physical activity (Gucciadi et al., 2016; Perrier and Ginis, 2016) but provide limited consideration; Gucciadi et al., (2016) focuses on physical activity by undertaking a scoping review around storytelling and self-management interventions for people with chronic illness. Perrier and Ginis (2016) identify physical activity as one of many health promoting behaviours which are reviewed. A systematic approach to review is needed that can provide greater

insight to the outcomes from such intervention but also include identification of the psychosocial mechanisms which can explain such outcomes. To the best of the author's knowledge, no systematic review has explored the literature around how the core elements of storytelling can cause specific outcomes and promote physical activity in the chronically ill. The purpose of this review was to develop an understanding of the perceived main benefits of storytelling and how this can influence the chronically ill to partake in physical activity.

#### Methodology

An integrative review was undertaken (Whittemore and Knafl, 2005). This included three phases, a) search b) appraisal c) synthesis. The PRISMA (Preferred reporting items for systematic review and meta-analysis) flow diagram (Moher et al., 2009) was used to represent the search processes. The ENTREO (Enhancing transparency in reporting the synthesis of qualitative research) 21 item checklist was adhered to for the reporting of the synthesis (Tong et al., 2012). See supplementary file for a completed checklist. A subtle-realist paradigmatic position was assumed. This paradigmatic view acknowledges the individual nature of experience whilst seeking to establish 'common realities' that others can relate to. This is in contrast to a realist ontological position. This philosophical position values the unique expressions from individuals and has a subjective epistemology but seeks to focus on the common or most prevalent features of experience and perception of a phenomena. This paradigmatic position recognises that the perceptions and experiences of people do not preclude the existence of external phenomena (Hammersley, 1992). For the purpose of this review we view experiences as uniquely shared but with common features identified within the phenomena (in this case themes from the qualitative synthesis). However, this paradigm does not claim absolute certainty in findings like a realist would (Duncan and Nicol, 2004).

#### Eligibility criteria

A standardised criteria PICOS (participant, intervention, control, outcome and study design) was used to document the eligibility criteria of included qualitative studies;

P) Participants are to be included if they have been clinically diagnosed with a chronic illness. Participants within each study must be eighteen years old and above.

I) The intervention must have included a storytelling intervention. The study should include the psychosocial effects of storytelling for stakeholders or the role of storytelling on physical activity promotion. Varied formats of the intervention were acceptable including written, shared in a group or via the internet. Fiction based studies were not included so a comparison could be made considering lived experiences.

C) Any active or inactive control group was permitted as well as studies that did not incorporate a control group.

O) Outcome measures were required to capture the effects of storytelling on the perceptions and behavioural intentions of chronically ill participants, or data that captures the effects of storytelling on physical activity involvement. Outcome measure needed to consider physical activity behaviour and impact, or captured psychosocial concepts such as self-efficacy, social support were required.

S) Studies must have been published from inception until 2019. Studies had to be translated into English, only studies coined in European and English-speaking countries were accepted. The study design must be qualitative, quantitative or mixed methods. All review, thesis, or conference abstracts, were excluded.

The search process

Searches were carried out until 1 November 2019 adhering to guidelines by McGowen et al (2015). The sources used to search relevant studies were subject-specific electronic databases including; Medline, PsychInfo, PubMed, Cochrane, and TRIP database. The first 20 pages of both Science Direct and Google Scholar were used as supplementary searches. A variety of search terms were used to obtain results, words included storytelling, OR narratives AND chronic illness OR diabetes OR Chronic Obstructive Pulmonary Disease OR Cardiovascular Disease OR Multiple Sclerosis, OR Cancer OR Spinal Cord Injury OR Parkinson's OR Stroke AND physical activity OR physical activity.

#### Study Selection

Studies identified as relevant were then read and screened by the author CB to establish studies that suited the eligibility criteria.

#### Data collection process

A predefined extraction form was identified to document methodology, aim, eligibility criteria, the key intervention details and data collection. In addition, patient demographic variables were noted including the age, gender, type of chronic illness and geographical location of the participants were identified.

#### *Quality appraisal – COREQ*

The quality assessment of qualitative studies was undertaken using the consolidated criteria for reporting qualitative research (COREQ) (Tong et al., 2007) based on a 13-item version (Soundy et al., 2016) to identify fatally flawed articles (Dixon-Woods and Fitzpatrick, 2001). Fatally flawed articles are those which scored less than 3/13 from the COREQ and considered to present questionable results. No article identified met this criteria.

#### Cochrane risk of bias

The Cochrane risk of bias tool was implemented for each quantitative (n=2) and mixed method study (n=2) (Higgins and Green, 2011). No studies were removed from the review due to quality.

#### Synthesis

Data analysis was guided by the general requirements identified by Whitmore and Knaff (2005). Data was reduced into qualitative and quantitative formats. A qualitative led approach was undertaken which required integration of quantitative findings after the synthesis of qualitative information was completed. The integration was undertaken by using quantitative findings to expand and give context to the qualitative themes. A four-stage thematic synthesis was undertaken which was led by qualitative analysis strategies identified by Bazeley (2013). Stage 1; both authors undertook blinded open coding. Authors identified codes and comments on the results section of each included article. Once completed authors discussed the comments made and agreed terms used to describe comments. Stage 2; The lead author undertook a process of mind mapping to generate ideas of themes which represented the codes identified from Stage 1. The lead author presented a justifiable case to the second author who acted as a 'critical friend'. The primary purpose of this was to use the second author as a spring board for ideas and to provide critical comments and questions around the thematic structure and placements of themes in order to group and re-group content. Stage 3; Using an agreed thematic structure the lead author pasted all study findings into the thematic table. This was then used to define theme, and details codes. Negative cases were considered at this stage. The second author considered and agreed the final structure. Stage 4; Finally, two steps were taken by the lead author. First subthemes were reduced by removing any that did not have at least two articles supporting them. Second integration of quantitative data was undertaken by elaborating any qualitative theme or subtheme that related to impact or signified change following an intervention.

#### **Results**

Study Characteristics/ Demographics

A total of 818 participants (191 male, 348 female, 279 unknown) were involved in the studies. The classification of chronic conditions included; spinal cord injury (n=57), diabetes (n=420), cancer (n=158), Multiple Sclerosis (n=16), Parkinson's Disease (n=42), psychiatric disorders (n=42), aphasia (n=27) and dementia (n=56). Five studies took place in the USA, four in Europe and one in New Zealand. The methodology included explanatory mixed methods studies using randomised control trials (n=5), ethnography (n=3), descriptive narrative (n=4), and multiple case design (n=2). The PRISMA flow diagram (Moher et al., 2009) can be seen in Figure 1. See the supplementary file for further search processes and demographics.

#### Quality appraisal

Quality appraisal is provided in the supplementary file. No study was excluded due to quality.

#### *Synthesis*

Four key themes were identified; (1) <u>Group processes that enhanced intervention outcomes</u>, (2) psychosocial factors that influence storytelling, (3) perceived outcomes relating to storytellying and (4) perceived benefits of physical activity. For the purpose of the synthesis we have provided a study number system<sup>1</sup> to consider the representativeness of each theme. A complete breakdown and full thematic table are available in the supplementary file.

#### Theme 1: Group processes that enhanced intervention outcomes

The theme includes a summary of results relating to the aspects of storytelling required for an intervention to be executed. This theme has two subthemes.

<sup>&</sup>lt;sup>1</sup> 1 = Perrier et al., (2013); 2 = Corsten et al., (2015); 3 = Njeru et al., (2015); 4 = Smith et al., (2014); 5 = Wright St-Clair (2003); 6 = Piana et al., (2009); 7 = Sitvast (2013); 8 = Falzon et al (2015); 9 = Phillips et al (2010); 10 = Comellas et al (2015); 11 = Nguyen et al., (2018), 12 = Nguyen et al., (2017); 13 = Gucciardi et al., (2019); Soundy et al., (2019).

#### Subtheme 1.1: The impact and use of language as a part of storytelling

This subtheme is supported by four articles (2,4,5,9,13,14; 6/14). This theme focuses on the influence of the wording of stories to illustrate the impact of illness, this was often done using metaphors to determine the significance of the story and draw the listener in. Metaphors allow the storyteller to express their memories and past experiences in their own creative way which cannot be described through standard vocabulary (5). In addition, the studies exemplify that dialogue can hold the attention of the listener and cause personal reflection, triggering behaviour change (2, 4). One example of this is from a storytelling group used to help people with dementia (9). Compared to an inactive control group, the storytelling group identified significantly improved communication and feelings of pleasure at week 3,6 and 7 from a six-week intervention.

Subtheme 1.2: The importance of environment and an atmosphere of trust for storytelling

This subtheme is supported by six articles (1,2,4,8,13,14; 6/14). This theme focuses on the
influence of the environment within a story when shared. Participants often identified the
importance of creating a context which has the ability to relate and immerse individuals in the
stories, this unearthed feelings and memories of the participants which grasped their attention (2,4).

The studies also depicted the importance of a trusting atmosphere within the intervention, to
provoke participants to open up about their feelings without fear. Study (8) quantified the
importance of trust by illustrating a significant increase (p<0.001) of participant's trust for a peer
led storytelling group compared to an expert giving information and advice. Two studies (13,14)
highlighted the importance of homogenous groups (gender, age, illness classification, geographic,
newly diagnosed) to enhance sharing and interactions.

#### Theme 2: Psychosocial factors that influence storytelling

This theme 'includes a summary of results relating to the psychosocial elements or characteristics that occur within the storytelling intervention. This theme has four subthemes.

#### Subtheme 2.1: Social comparison

This subtheme is supported by six articles (1,2,4,5,13,14; 6/14). Participants related to the stories being told and drew comparisons with their similarities and dissimilarities. Social upward comparison motivated participants to be active due to their admiration of other participants reaping benefits from their healthy active lifestyle (1,2,13,14). Social downward comparisons made participants feel fortunate to be in the position they were in and strive to continue to enhance their quality of life (1,2). Participants also voiced the value comparison had in causing them to feel less isolated and alone when relating to other participants hardships (2,4,6,14).

#### Subtheme 2.2: Social support

This subtheme is supported by seven articles (1,2,3,4,6,13,14; 7/14). This theme focuses on the social support participants gained when discussing their chronic illness with others. It can be inferred many of the participants had a heightened sense of confidence and felt the ability to cope with their disease due to encouragement from others in the group (1,2,7,13,14). Support and encouragement from peers and health care professionals motivated participants to take part in physical activity and, make changes to improve their quality of life (1,3,13,14).

#### Subtheme 2.3: Perceived control

This subtheme is supported by five articles (2,3,5,13,14; 5/14). This theme focuses on the differing proportions of control chronically ill participants feel, which can be expressed to others. Some participants start their stories by discussing the loss of control they felt, due to the gradual deterioration of their body which they are unable to eradicate despite their efforts (5,3). Participants also articulate embracing the unpredictability of their condition. Many participants expressed an

ability to take back control of their life (2,3,5,13) by continuing to do the things they enjoy, such as exercising and working (2,3,5).

#### Subtheme 2.4: Self-reflection

This subtheme is supported by seven articles (1,2,4,5,6,7,14; 7/14). This theme focuses on self-reflection as one of the key mechanisms for (re)creating the plot of one's own story. Self-reflection includes a process of looking back at how they once felt about their disease, how they feel in the present and in contrast to how others experience illness. Reflecting on past experiences enlightened participants as to how they had progressed from previous negative circumstances, which was motivation for continued improvement (1,2,4). Self-reflection appeared to enable participants to normalise the experience of illness and accept it, bringing meaning and understanding to their chronic illness (2,6). Participants also expressed connecting with their emotions and feelings, which had psychological benefits (2,4,7,14).

#### Theme 3: Perceived Outcomes Relating to Storytelling

This theme includes a summary of results related to the consequences of the storytelling interventions for the participants. This theme has four subthemes.

#### Subtheme 3.1: Social identity

This subtheme is supported by eight articles (1,2,3,5,6,7,8,12,14; 8/14). This theme focuses on how individuals come to terms with their social identity after diagnosis of a chronic condition. The master plots of the stories told by individuals were split in the following ways; (a) a focus on being restored to who they once were by being able to get back to activities or roles they used to uphold.

(b) a focus on positive changes which pushed them towards new goals and achievements creating a new social identity and improved self-efficacy (1,2,5,8,14). This can be reinforced with quantitative

measures. For instance, in one study (8) the mean self-efficacy on a Likert scale after listening to a story by a chronically ill patient was 4.04, compared to a mean of 3.11 for listening to factual information. Others noted acceptance of the disease as a part of themselves, this inferred accepting the present circumstances and perceived limitations (3,5,6,7).

#### Subtheme 3.2: Knowledge

This subtheme is supported by nine articles (3,4,5,6,7, 8, 12,13,14; 9/14). This theme focuses on the increased knowledge chronically ill patients gain from listening to others living with their disease. Storytelling can be used as an informative mechanism to enhance participants understanding of how to control their symptoms (5,6,7,8). Quantitative measures supported this showing belief about exercise risks were higher in patients listening to a breast cancer survivors story on exercise, with a mean score on the Likert scale of 3.07, than factual information, the mean score was 2.56 (8). Storytelling was noted as an excellent communication tool for synthesised knowledge as it is thought-provoking and engaging, therefore participants pay attention to the information being presented to them. (4,6,14).

#### Subtheme 3.3: Motivation

This subtheme is made up of nine articles (1,2,3,5,6,7,10,12,13,14;11/14). This theme focuses on motivation causing the transformation of perceptions and behavioural intentions into actions. Participants expressed feeling internal motivation to continue exercising and regulating their health due to the psychological and physical benefits they gain, and to stay fit for any interventions in the future which would benefit them (1,2,3,5,6,10,12,14). This was backed up quantitatively, as one study found that after discussion circles individuals taking the SDSCA survey (Summary of Diabetes Self-Care Activities measure) reported increased physical activity on average from 3.1 to 4.6 days of exercise for at least 30 minutes per day (p=.04)° (10). Another study reported significantly different physical activity at 12-months compared to a didactic control condition (11).

Additionally, participants articulated extrinsic motivation to keep fit to support family members (1,3,7).

#### Theme 4: Perceived benefits of physical activity

This theme includes a summary of results relating to the benefits of physical activity expressed by participants in the storytelling intervention. This theme has four subthemes.

#### Subtheme 4.1: Enhancing quality of life

This sub-theme is made up of seven articles (1,2,3,4,5, 11,12,14; 7/14). This theme focuses on the effect of physical activity on the quality of life of chronically ill patients. Participants convey having improved physical function and relief of their symptoms (3,4,11, 12). For instance, at 12-month follow up participants with hypertension recorded significantly lower blood pressure compared to the control group (didactic information group) (11). Other participants spoke of the psychological support physical activity has provided them with, participants noted gaining an instant release of stress and feelings of hope for the future. (1,3).

#### Subtheme 4.2: A distraction

This theme is made up of two articles (1,5; 2/14). This theme focuses on physical activity as a distraction from the pain and suffering chronically ill patients can feel (1,5). Some participants that expressed a sad or tragic narrative master plot appeared to benefit by focusing their mind on physical tasks and socialising with others. The storytelling intervention prevented them from focusing on their chronic condition. Therefore, physical activity can provide temporary relief from their negative thoughts.

#### Subtheme 4.3: Meaning and fulfilment

This theme is made up of three articles (2,3,14; 3/14). This theme focuses on participants beliefs about how physical activity affects the meaning and fulfilment of their life. Participants stated that physical activity has increased their independence and unearthed their hidden abilities providing fulfilment (2,3). Other participants focus on exercising in conjunction with activities that are meaningful and enjoyable to them.

#### **Discussion**

The current review identified the importance of storytelling as an intervention which can aid biopsychosocial well-being. This is the first review to solely consider storytelling within a context of
physical activity promotion. Several psychosocial mechanisms occurred which may have explained
the main benefits of the intervention. These included social support, and social comparison from
peers and opportunities for self-reflection and increased perceptions of control over the illness. The
main outcomes from using storytelling intervention included increased participant knowledge and
changes in their social identity. Participants appeared to be motivated to make positive behavioural
changes following interventions. This finding may have been enhanced by including physical
activity as part of the intervention. Using physical activity as a component of the interventions was
associated with increased quality of life and the ability to maintain meaning and fulfilment in life.

Psychosocial factors which influence storytelling

Several psychosocial mechanisms may explain the results found, including; (a) social comparisons, that likely helped participants to feel less isolated as they related to other's hardships. When comparisons are positive they are likely an integral mechanism that enhances a physical activity social identity. The evolution of social identity is a central need following a chronic illness (Higgs and Soundy, 2020) (b) Social support, which could increase motivation, confidence and perceived ability to cope and manage their condition (Perrier et al., 2013, Corsten et al., 2015, Sitvast 2013; Smith et al., 2014). (c) Perceived control; appeared to be enhanced through hearing stories of how

others coped. Perceived control is important in stimulating a change of perception and behavioural intention for the participants. This has not been identified in past reviews (Moreu et al., 2018, Gucciardi et al., 2016, Schoenau and Jackson, 2016). Improved physical activity confidence likely transcends to other aspects of an individual's life which includes enhanced autonomy and choice (Soundy et al., 2014) (d) Self-reflection; the findings demonstrate that storytelling enhances the self-reflection process which appears to influence their ability to psychologically adapt, their perceived confidence and social-identity. This has been an aspect which has been identified in past storytelling interventions (e.g., Nurser et al., 2018; Reid and Soundy, 2019) and (e) an ability to psychosocially adapt and a safe and supported environment to share and reveal personal information and feelings. This has recently been found in other storytelling studies (e.g., Chow, 2018; D'Cruz et al., 2019).

#### Outcomes linking to physical activity

The results identified specific outcomes of storytelling which lead to participants taking part in physical activity. This may be explained through enhanced self-efficacy (Perrier et al., 2013, Njeru et al., 2015) and increased knowledge and understanding, which enabled them to take actions that could enhance control of their symptoms (Wright-St Clair, 2003, Piana et al., 2009, Sitvast., 2013) Additionally, results showed the subsequent increased participation of physical activity was associated with increased meaning and fulfilment into the lives of the chronically ill (Corsten et al., 2015, Njeru et al., 2013). Further studies are required to confirm the current findings.

#### Implications:

Storytelling interventions appear useful as a part of physical activity promotion and behavioural change. The current evidence identifies the potential of storytelling to be a cost-effective intervention that supports patient's self-management and physical activity behaviours. Health care

professionals need to consider if storytelling or particular story types are allowed within clinical practice and how stories are used within the culture. There may be a need to understand the plots of the common stories told by people and how these stories can be assisted by others.

The current results suggest that storytelling physical activity interventions likely provide a unique environment where social comparison can enable people's ability to share with one another. The ability to share within this environment may be enhanced by relatedness and social comparison. It is important to consider how health care professionals may use these findings to support people with chronic illness. This may be achieved in several ways; (a) through using a screening tool that relates to storytelling. Our research group has identified the model of emotion, adaptation and hope (MEAH; see www.meah.rocks). The MEAH provides a broader, re-considered and combined picture of psychological adaptation. Illness story plots of chronic illness can be mapped onto the MEAH (Soundy, 2018) and this can be used as the basis for an intervention because the MEAH focuses on the relative difficulties experienced by individuals (see Appendix A). Benefit of a storytelling intervention is possible when a negative score identified within any domain of the MEAH. (b) Once a need for an intervention has been identified allowing principles for interaction engagement are required. This includes the encouragement of sharing experiences of suffering by listening and the use of empathy. This may be assisted by exploring an individual's metaphor. Metaphor is a device by which one concept, experience or object is defined or described in terms of another (Cameron, 2003). They are particularly prevalent when people are talking about complex, difficult or emotionally-charged experiences such as cancer (Gibbs and Franks, 2002) and end-oflife care (Semino et al., 2017;2018). Finally, the results support the need to encourage people with chronic illness to consider the stories of others who they admire who may be facing a similar situation to themselves. Further work is needed to combine such principles within storytelling interventions.

#### Limitations

The following limitations should be considered; (a) limited number of studies currently available and a lack of fiction based interventions. This may have caused our findings to focus on particular psychosocial constructs or outcomes which limits current understanding. (b) number of illnesses considered and the subsequent heterogeneity of studies included mean the implication to each condition may be general at this stage. Whilst we offer general principles, guidance across illness conditions would need modification in future research. (c) a focus on the most common themes derived by the authors and past experience means the diversity of findings may be lost. Individuals are required to consider and critically evaluate the implication for their own settings. (d) the quantitative representation of themes given in the results is influenced by the fact some experimental studies did not report on qualitative findings. This may have meant that key processes and understanding of how and why the interventions create impact is missing, and (e) interventions used significantly more participants with diabetes compared to other chronic illnesses. This may mean implications are more suited to this group.

#### **Conclusion**

This research has indicated that storytelling is an effective tool in bio-psychosocial well-being and promoting physical activity for individuals with a chronic illness. Health care professionals will benefit from understanding the psychosocial mechanism which explain change and considering how these elements can be enhanced within their own settings. The potentially wide range of psychosocial benefits of these intervention warrant further careful analysis and consideration.

#### References

References in *italics* indicates those included in the review

Akard, T. F., Dietrich, M. S., Friedman, D. L., Hinds, P. S., Given, B., Wray, S., Gilmer, M. J. (2015). Digital storytelling: An innovative legacy-making intervention for children with cancer. *Paediatric Blood and Cancer*, 62; 658-665.

Atkinson, S., Rubineli, S. (2012). Narrative in cancer research and policy: voice, knowledge and context. Critical Reviews in Oncology/Hematology, 84: S11-S16.

Belza, B., Walwick, J., Taylor, M. (2004). Older adult perspectives on physical activity and exercise: voices from multiple cultures. Prev Chronic Dis. 1:A09.

Capecci, J. and Cage, T. (2012). Living proof: Telling your story to make a difference (1<sup>st</sup> edition). Granville Circle Press, USA.

Corsten, S., Schimpf, E., Konradi, J., Keilmann, A. and Hardering, F. (2015). The participants' perspective: how biographic-narrative intervention influences identity negotiation and quality of life in aphasia. International Journal of Language & Communication Disorders, 50; 788-800.

Comellas, M., Walker, E., Movsas, S., Merkin, S., Zonszein, J. and Strelnick, H. (2009). Training Community Health Promoters to Implement Diabetes Self-Management Support Programs for Urban Minority Adults. The Diabetes Educator, 36; 141-151.

Charon, R. (2006). Narrative medicine. Honoring the stories of illness. Oxford; Oxford University Press.

Chow, E. O. W. (2018). Narrative group intervention to reconstruct meaning of life among stroke survivors: A randomised clinical trial study. *Neuropsychiatry*, 8; 1216-1226

D'Cruz, K., Douglas, J., Serry, T. (2019). Narrative storytelling as both an advocacy tool and a therapeutic process: Perspectives of adult storytellers with acquired brain injury. *Neuropsychological Rehabilitation*, 1; 1-21.

Dixon-Woods, M. Fitzpatrick, R. (2001). Qualitative research in systematic reviews. *BMJ*, 323; 765-766.

Ellis, Terry and Robert, W. (2013). Physical activity behavior change in persons with neurologic disorders: Overview and examples from Parkinson's disease and multiple sclerosis. *Journal of Neurologic Physical Therapy*, 37; 85–90.

Falzon, C., Radel, R., Cantor, A. and d'Arripe-Longueville, F. (2014). Understanding narrative effects in physical activity promotion: the influence of breast cancer survivor testimony on exercise

beliefs, self-efficacy, and intention in breast cancer patients. Supportive Care in Cancer, 23; 761-768.

Gucciardi, E., Jean-Pierre, N., Karam, G. and Sidani, S. (2016). Designing and delivering facilitated storytelling interventions for chronic disease self-management: a scoping review. *BMC Health Services Research*, 16(1).

Gucciardi, E., Richardons, A., Aresta, S., Karam, G., Sidani, S., Beanlands, H., Espin, S. (2019). Storytelling to support disease self-management by adults with Type 2 diabetes. Canadian Journal of Diabetes, 43; 271-277.

Higgs, R., Soundy, A. (2020). Factors which influence risk taking and the evolution of social identity in stroke narratives: A thematic synthesis. Behavioral Sciences, 10: 46.

Higgins JPT, Green S (editors) (2011). *Cochrane Handbook for Systematic Reviews of Interventions* Version 5.1.0 [updated March 2011]. The Cochrane Collaboration. Available at <a href="http://handbook.cochrane.org">http://handbook.cochrane.org</a>.

Høybe, M. T., Johansen, C., Tjørnhøj-Thomsen, T. (2004). Online interaction. Effects of storytelling in an internet breast cancer support group. *Psycho-oncology*, 14; 211-220.

Hsieh, E. (2010). Stories in action and the dialogic management of identities: Storytelling in transplant support group meetings. *Research on Language and Social Interaction*, 37; 39-70.

Ley, C., Barrio, M. R. (2012). A narrative review of research on the effects of physical activity on people living with HIV and opportunities for health promotion in disadvantaged settings. *African Journal of AIDS Research*, 11; 123-133.

Lugmayr, A., Sutinen, E., Suhonen, J., Sedano, C. I., Hlavacs, H., Montero, C. S. (2017). Serious storytelling – a first definition and review. *Multimedia tools and Applications*, 17; 15707-15733.

Moher, D., Liberati, A., Tetzlaff, J. and Altman, D. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *BMJ*, 339; b2535-b2535.

Moreau, K., Eady, K., Sikora, L. and Horsley, T. (2018). Digital storytelling in health professions education: a systematic review. *BMC Medical Education*, 18; 208.

Morey, M., Pieper, C., Crowley, G., Sullivan Jr, R. and Puglisi, C. (2008). Exercise Adherence and 10-Year Mortality in Chronically Ill Older Adults. American Geriatrics Society. [online] Available at: https://onlinelibrary.wiley.com/doi/full/10.1046/j.1532-5415.2002.50602.x [Accessed 1 Mar. 2019].

NCD Risk Factor Collaboration (NCD-RisC). (2016). Worldwide trends in diabetes since 1980: a pooled analysis of 751 population-based studies with 4.4 million participants. The Lancet, 387: 1513-1530.

Nguyen, H. L., Allison, J. J., Ha, D. A., Chiriboga, G., Ly, H. N., Tran, H. T., et al. (2017). Culturally adaptive storytelling intervention versus didactic intervention to improve hypertension control in Vietnam: a cluter-ranodmised controlled feasibility trial. Pilot and Feasibility Studies, 3; 22.

Nguyen, H. L., Ha, D. A., Goldberg, R. J., Kiefe, C. I., Chiriboga, G., Ly, H. N., et al. (2019). Culturally adaptive storytelling intervention versus didactic intervention to improve hypertension control in Vietnam- 12 month follow up results: a cluster randomised controlled feasibility study.

Njeru, J., Patten, C., Hanza, M., Brockman, T., Ridgeway, J., Weis, J., Clark, M., Goodson, M., Osman, A., Porraz-Capetillo, G., Hared, A., Myers, A., Sia, I. and Wieland, M. (2015). Stories for change: development of a diabetes digital storytelling intervention for refugees and immigrants to minnesota using qualitative methods. BMC Public Health, 15; 1311.

National Health Service (2014). Five Year Forward View. [ebook] NHS, UK. Available at: https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf [Accessed 2 Mar. 2019].

Nurser, K. P., Rushworth, I., Shakespeare, T., Williams, D. (2018). Personal storytelling in mental health recovery. Mental Health Review Journal, 23; 25-36.

Perrier, M., Smith, B. and Latimer-Cheung, A. (2013). Narrative environments and the capacity of disability narratives to motivate leisure-time physical activity among individuals with spinal cord injury. Disability and Rehabilitation, 35; 2089-2096.

Perrier, M., Ginis, K. A. (2016). Changing health-promoting behaviours through narrative interventions: A systematic review. *Journal of Health Psychology*, 23; 1499-1517.

Petri, H. (1990). Motivation: Theory, Research and Applications. 3rd ed. Belmont, Calif.: Wadsworth Pub. Co., pp.3,4,5.

Piana, N., Maldonato, A., Bloise, D., Carboni, L., Careddu, G., Fraticelli, E., Mereu, L. and Romani, G. (2010). The narrative-autobiographical approach in the group education of adolescents with diabetes: A qualitative research on its effects. Patient Education and Counseling, 80; 56-63.

Phillips, L., Reid-Arndt, S. and Pak, Y. (2010). Effects of a creative expression intervention on emotions, communication, and quality of life in persons with dementia. Nursing Research, 59; 417-425.

Schoenau, M. and Jackson, I. (2016). Effectiveness of storytelling interventions on psychosocial outcomes in adult patients with a life-threatening illness. JBI Database of Systematic Reviews and Implementation Reports, 14; 52-60.

Sitvast, J. (2013). Self-management and Representation of Reality in Photo Stories. Advances in Nursing Science, 36; 336-350.

Smith, B., Tomasone, J., Latimer-Cheung, A. and Martin Ginis, K. (2014). Narrative as a knowledge translation tool for facilitating impact: Translating physical activity knowledge to disabled people and health professionals. Health Psychology, 34(4), 303-313.

Soundy, A. (2018). Psycho-emotional content of illness narrative master plots for people with chronic illness: Implications for assessment. World Journal of Psychiatry, 8: 79-82.

Soundy, A., Collett, J., Lawrie, S., Coe, S., Roberts, H., Hu, M., Bromley, S., Harling, P., Reed, A., Coeberg, J., Carroll, C., Dawes, H. (2019). A qualitative study on the impact of First Steps – A peer-led educational intervention for people newly diagnosed with Parkinson's Disease. Behavioural Sciences, 9; 107.

Soundy, A., Freeman, P., Stubbs, B., Probst, M., Coffee, C., Vancampfort, C. (2014). The transcending benefits of physical activity for individuals with schizophrenia: A systematic review and meta-ethnography. Psychiatry Research, 220: 11-19.

Soundy, A., Reid, K. (2019). The psychosocial impact and value of participating in a storytelling intervention for patients diagnosed with cancer: An integrative review. *Open Journal of Therapy and Rehabilitation*, 7: 3577.

Soundy, A., Roskell, C., Smith, B. (2013). Are you an artificial person? Lessons from mid Staffordshire. Physiotherapy, 99; 185-186.

Soundy, A., Roskell, C., Elder, T., Collett, J. and Dawes, H. (2016). The Psychological Processes of Adaptation and Hope in Patients with Multiple Sclerosis: A Thematic Synthesis. *Open Journal of Therapy and Rehabilitation*, 04(01), pp.22-47.

Soundy, A., Smith, B., Cressy, F., Webb, L. (2010). The experience of spinal cord injury: using Frank's narrative types to enhance physiotherapy undergraduates' understanding. Physiotherapy, 96: 52-58.

Soundy, A., Smith, B., Butler, M., Minns Lowe, C., Dawes, H., Windward, C. H. (2010). A qualitative study in neurological physiotherapy and hope: Beyond physical improvement. Physiotherapy Theory and Practice, 26: 79-88.

Stubbs, B., Vancampfort, D., Hallgren, M., Firth, J., Veronese, N., Solmi, M., et al. (2018). EPA guidance on physical activity as a treatment for severe mental illness: a meta-review of the evidence and position statement from the European Psychitric Assoication (EPA), supported by the international organisation of physical therapists in mental health (IOPTMH). *European Psychiatry*, 54; 124-144.

Tong, A., Flemming, K., McInnes, E., Oliver, S. and Craig, J. (2012). Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Medical Research Methodology*, 12(1).

Tong, A., Sainsbury, P. and Craig, J. (2007). Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist. *International Journal for Quality in Health Care*. 2007, 19; 349 – 357.

The King's Fund. (2019). Long-term conditions and multi-morbidity. [online] Available at: https://www.kingsfund.org.uk/projects/time-think-differently/trends-disease-and-disability-long-term-conditions-multi-morbidity [Accessed 1 Mar. 2019].

World Health Organisation.com. (2019). WHO | Integrated chronic disease prevention and control. [online] Available at: https://www.who.int/chp/about/integrated\_cd/en/ [Accessed 6 Mar. 2019].

Whittemore, R., Knafl, K. (2005). The integrative review: updated methodology. Journal of Advanced nursing, 52: 546-553.

Wright-St Clair (2003). Storymaking and Storytelling: Making Sense of Living with Multiple Sclerosis. Journal of Occupational Science, 10; 46-51.

#### Appendix A

#### The Model of Emotions, Hope and Adaptation Screening Tool

#### Version 3.3

#### Hope and Adaptation Questions

Please answer the following five questions. The questions will relate to an aspect of your current situation to which you are finding it difficult to adapt. Examples of this include adapting to the following; experiences relating to the process of diagnosis, the impact of the diagnosis, changes or losses in relationships in the work place, socially or at home, the inability to be independent, and the loss of an identity like being an athlete or father. This assessment and screening tool is designed to identify the need you have for support and is able to track your process of adaptation to the difficulty over time. During subsequent meetings, you may like to track other difficulties.

Note: The numbers identified on the left-hand side of each scale distinguish responses by a rating relating to hope, adaptation and emotions. Positive or negative numbers further away from zero illustrate a more intense response.

### 1. Complete the sentence below and name the one aspect of your adaptation that you are finding most difficult?

I am finding considerable/most difficulty adapting	
to	

### 2.Regarding the difficulty you have identified how hopeful are you right now that you can or will overcome it?

- · · · · · · · · · · · · · · · · · · ·	
Level of Hope associated with difficulty	<u>Circle</u> a number reflecting the statements on the left
I am completely certain and have no doubt that I will be able to overcome this difficulty	+4
I am certain that I will be able to overcome this difficulty	+3
I believe it is likely that I will overcome this difficulty	+2
I believe it is possible to overcome this difficulty	+1
I accept that it might not be possible to overcome this difficulty	0
I feel uncertain and don't know if this difficulty can be overcome	-1
I feel that it is likely that I wont overcome this difficulty	-2

I have little hope or ability to overcome this difficulty	-3
I see neither hope or ability to overcome this difficulty	-4

## 3. Regarding the difficulty you have identified do you feel able to psychologically adapt to it right now? Circle a number by considering the statements.

Ability to adapt to the difficulty	<u>Circle</u> a number reflecting the statements on the left
I am able to positively embrace and use this difficulty for benefit	+4
I am able to fully accept and embrace this difficulty	+3
I am able to fully accept this difficulty	+2
I acknowledge this difficulty but can't fully accept it	+1
I am able to acknowledge this difficulty	0
I struggle with acknowledging this difficulty	-1
I find it difficult to accept this difficulty	-2
I find it very difficult to accept this difficulty	-3
I reject and cannot accept this difficulty	-4

## 4. What level of energy to you have today right now with regards to dealing with the difficulty you have identified. Please mark it on a scale from extremely high to extremely low

Energy Level to deal with the difficulty	<u>Circle</u> a number reflecting the statements on the left
I feel very highly energised to deal with this difficulty	+4
I feel highly energised to deal with this difficulty	+3
I feel moderate levels of energy to deal with this difficulty	+2
I feel above average levels of energy to deal with this difficulty	+1
I feel average or normal levels of energy to deal with this difficulty	0
I feel below average levels of energy to deal with this difficulty	-1
I feel moderately low levels of energy to deal with this difficulty	-2

I feel little energy available to deal with this difficulty	-3
I feel very little energy available to deal with this difficulty	-4

## 5. Please score how you feel about the difficulty you have identified in a range from pleasant to unpleasant

Valence or Pleasantness on how you feel about the difficulty	<u>Circle</u> a number reflecting the statements on the left
I have extremely positive feelings regarding the difficulty I am facing	+4
I have positive feelings regarding the difficulty I am facing	+3
I have pleasant feelings regarding the difficulty I am facing	+2
I have above average feelings regarding the difficulty I am facing	+1
I have average or normal feelings regarding the difficulty I am facing	0
I have below average feelings regarding the difficulty I am facing	-1
I have below average or unpleasant feelings regarding the difficulty I am facing	-2
I have negative feelings regarding the difficulty I am facing	-3
I have extremely negative feelings regarding the difficulty I am facing	-4