Cognitive Representations Of Disability Behaviours In People With Mobility Limitations: Consistency With Theoretical Constructs.

Diane Dixon & Marie Johnston

Department of Psychology, University of Aberdeen

All Correspondence to:

Dr Diane Dixon

Department of Psychology,

University of Stirling

Stirling

FK9 4LA

Phone: + 44 (0)1786 466840

FAX: + 44 (0)1786 467641

E-mail: Diane.Dixon@stir.ac.uk

ABSTRACT

Purpose: Disability is conceptualised as behaviour by psychological theory and as a result of bodily impairment by medical models. However, how people with disabilities conceptualise those disabilities is unclear. The purpose of this study was to examine disability representations in people with mobility disabilities.

Method: Thirteen people with mobility disabilities completed personal repertory grids (using the method of triads) applied to activities used to measure disabilities. Ten judges with expertise in health psychology then examined the correspondence between the elicited disability constructs and psychological and medical models of disability.

Results: Participants with mobility disabilities generated 73 personal constructs of disability. These constructs were judged consistent with the content of two psychological models, namely the theory of planned behaviour and social cognitive theory and with the main medical model of disability, the International Classification of Functioning Disability and Health.

Conclusions: Individuals with activity limitations conceptualise activities in a manner that is compatible with both psychological and medical models. This ensures adequate communication in contexts where the medical model is relevant, e.g. clinical contexts, as well as in everyday conversation about activities and behaviours. Finally, integrated models of disability may be of value for theory driven interdisciplinary approaches to disability and rehabilitation.

Introduction

The limitation in ability to perform particular actions, such as walking half a mile, climbing stairs and getting into and out of a chair contribute to indices of disability [1-4]. Psychology construes such activity limitations as behaviour and employs models of motivation, such as social cognition models, to provide a theoretical account of disability [5]. In contrast, biomedicine adopts impairment-based models in which disability is viewed as a result of underlying pathology [6,7]. In an endeavour to provide a theoretical framework that is able to reconcile the medical and psychological evidence bases, a model that integrates psychological and medical models of disability has been proposed [5,8]. Recent testing of this model demonstrated that it was able to account for more (57%) of the variance in walking limitations in an orthopaedic sample than either a medical or psychological model alone [9].

However, we have little knowledge of how people with disabilities conceptualise disability. Both medicine and psychology represent discipline specific expert knowledge systems and their conceptualisation of disability is consistent with those knowledge systems. It can be argued that people with disabilities also represent an expert knowledge system, in that they have personal knowledge of those disabilities. Indeed, self-management programmes for chronic illness have recognised this unique knowledge through the concept of an expert patient [10]. It is possible that an individual may employ evaluative constructs that relate to their bodily impairment which are consistent with medical models, e.g. walking half a mile makes my joints stiff, or they may use motivational constructs consistent with psychological models, e.g. walking half a mile takes too much effort. Alternatively, the evaluation of disability could take other forms, for example an age dependent model could be used, e.g. at my age I am lucky I can still climb stairs.

Personal models or representations of features of the world are important because individuals can be regarded as active problem solvers who use such representations both to guide their response to and to anticipate life events [11-13]. Personal representations related of illness are informed by abstract information gained from others such as health professionals and family and by an individual's own life experience. These personal models are important determinants of the response to illness [12]. People with disabilities are, therefore, likely to use their personal model of disability to guide their responses to that disability [12] and discrepancies between their personal model and an expert model held by healthcare staff may result in poor communication. It would be of interest therefore to investigate how people with disabilities conceptualise those disabilities and whether those conceptualisations are consistent with theoretical models of disability.

This study focuses on one of the most common forms of disability, namely locomotor disability [14]. The study examines how people with locomotor disabilities, associated with osteoarthritis of the hip or knee, represent those activities typically used to measure such disabilities and assesses how consistent those representations are with psychological and medical models of disability. Individual representations of locomotor disability were elicited from people with mobility disabilities using a repertory grid method [15]. These representations were then compared to the constructs in two psychological models, namely the theory of planned behaviour (TPB) [16] and social cognitive theory (SCT) [17] both of which have been successfully used to predict disability in a variety of clinical populations, including, joint replacement patients [18], stroke [19], rheumatoid arthritis [20], MI [21] and COPD [22]. The main medical model of disability is the WHO's International Classification of

Functioning Disability and Health (ICF); locomotor disability representations were also compared to the three central constructs in this model, namely, impairment, activity limitations and participation restrictions [7].

Method

Design

People with walking difficulties due to osteoarthritis were interviewed using repertory grid methods to elicit personal constructs (PCs) of four everyday physical activities. Expert judges compared the elicited constructs to the definitions of the theoretical constructs from two social cognition models, namely the TPB and SCT and to the constructs in the ICF.

Participants

Fifteen adults, aged over 65, were recruited into the study. Fourteen volunteers were recruited through an advertisement placed in a local newspaper that asked for people with mobility difficulties due to osteoarthritis and one following an announcement of the study at a meeting of the local Arthritis Care Group. All volunteers had osteoarthritis of one or more hip or knee joint; one volunteer had undergone total joint replacement of both hips and one was currently awaiting hip replacement surgery. Of the 15 original volunteers (9 female), 13 completed the study; 1 could not perform any of the behaviours presented (female) and 1 was unable to maintain attention on the task (male). The average age of the 13 participants who completed the study was 70.5 years (s.d. 7.9, range 59 - 83). Participants reported having had mobility difficulties for an average of 8.8 years (s.d. 10., range 0.5 – 30) and having suffered from osteoarthritis for an average of 17.2 years (s.d. 15.0, range 1 - 45). Seven of

the 13 participants reported a variety of comorbid conditions, including, coronary artery disease (2 participants), hypertension (2 participants), osteoporosis (2 participants) and type 2 diabetes (1 participant). Twelve judges with expertise in health psychology participated in the judgement task. All judges were members of the Health Psychology Research Group at the University of Aberdeen

Procedure

1. Eliciting representations of disability behaviours as PCs

The repertory grid method is reliant on the relationship between what are termed 'personal constructs' and 'elements'. The 'elements' were provided by the interviewer and were four activities, namely: getting in and out of a chair, walking outside of your home, climbing up and down stairs and walking inside your home. These activities were chosen because previous work had shown that people with osteoarthritis experience differing degrees of limitation when performing these activities [23]. The 'personal constructs' were the cognitive representations elicited in response to the presentation of the four 'elements', i.e. the four activities. The activities were presented using the sequential form of the method of triads [15]. A triad is a set of three activities; two of the activities are compared to identify how they are similar and then both are contrasted with the third activity. The four activities generated a total of 12 possible triads. Participants were asked to imagine themselves performing each activity prior to the presentation of the first triad and then each of the 12 triads was presented in turn. On presentation of each triad the participant was asked two questions, first; "In what way are these two activities the same and, therefore, different from this third activity?", and second; "In what way is

this (third) activity different?". The first and second questions produced 'emergent' and 'contrast' poles of each PC respectively.

2. Comparison of disability representations to psychological and impairment models

The PCs elicited during the repertory grid procedure were independently examined by two expert judges to identify an agreed set of non-overlapping PCs.

TABLE 1 ABOUT HERE

Psychological Models. Six different judges were given the definitions of the constructs in the TPB and SCT (see table 1). Judges were asked to assign the agreed non-overlapping elicited PCs to one or more of the psychological constructs or to a category labelled *'other'*. Using a 0% to 100% scale, the judges indicated how confident they were that a given PC represented the psychological construct used to label it.

Medical Model. Approximately, three months after the first comparison task the same 6 expert judges, together with an additional 4 judges, were given the WHO ICF definition of impairment, activity limitations and participation restrictions (see table 1). Judges assigned each PC to one or more of the ICF constructs or to a category labelled '*other*'; judges provided a confidence rating for each judgement as for the psychological constructs.

RESULTS

Disability representations

All participants who were able to complete the repertory grid study were able to generate PCs to differentiate between the four activities (table 2). Overall, 73 PCs were elicited and the judges agreed on 34 non-overlapping PCs (see Appendix). The most frequently elicited PCs were the need for *support* and the amount of *effort*

required to perform an activity: both these PCs were elicited from nine of the thirteen participants. Eight participants distinguished between the four activities in terms of how *easy* or *difficult* the activity was to perform. The majority of participants also used fear of *falling* to discriminate between the activities. *Pain* was elicited as a PC from four participants and *hurts* was elicited from one participant.

TABLE 2 ABOUT HERE

Disability representations compared to theoretical models

All eight psychological constructs from the TPB and SCT were employed by at least one judge to label the disability PCs. However, the goal, intention and subjective norm constructs were only used by 2, 2 and 1 judges respectively to label any of the 34 disability representations, consequently these constructs are not discussed further. Table 3 shows the psychological constructs that were used as labels by a majority ($\geq$4) of judges and the PCs of disability they labelled. All six judges used the outcome expectancy, attitude and perceived behavioural control constructs as labels.

However, there were some differences in the confidence with which the psychological constructs were assigned; self-efficacy was assigned with the lowest confidence rating of 55% (s.d. 20) and this was significantly lower than the ratings for outcome expectancy ($t(112)=-3.38$, $p \leq 0.001$) and sociostructural factors ($t(70)=-3.97$, $p \leq 0.001$). Judges frequently used the same pair of psychological constructs to label the same PC; attitude and outcome expectancy were paired on nineteen PCs and each of these two constructs was paired with sociostructural factors on eighteen PCs. Perceived behavioural control and self-efficacy were paired on nine PCs.

TABLE 3 ABOUT HERE

As shown in table 3, all three medical model constructs were used by a majority (>5) of judges to label the disability representations. All 10 judges used the impairment and activity limitations constructs as labels at least once. Activity limitations was used as a label with more confidence than either impairment or participation restrictions ($t(213)=-3.8$, $p\leq0.001$; $t(279)=2.8$, $p\leq0.01$, respectively). Multiple constructs were used to label the same PCs; nineteen PCs were labelled with all three constructs; twelve PCs were labelled as both activity limitations and participation restrictions and impairment and participation restrictions were paired on three PCs.

Further, constructs from both the psychological and medical models were used to label the same disability PCs. Outcome expectancy was paired with impairment on 6 PCs (hurts, breathless, dizzy, stiff, painful and lots of joint movement) and with activity limitations on 3 PCs (likely to fall, possibility of falling and will not fall). Activity limitations was also paired with perceived behavioural control on 3 PCs (comfortable to do, effortful and easy).

The ‘other’ category was used only once in the psychological constructs task. However, in the medical model task the same two judges used the ‘other’ category to label 12 and 21 PCs (22 PCs labelled ‘other’ in total by the two judges). Eleven of the 22 PCs were labelled ‘other’ by both judges. None of the PCs labelled as impairment by a majority of judges were also labelled ‘other’ by both judges. However, 6 of the 14 PCs labelled as activity limitations by a majority of judges and 1

of the 5 PCs labelled as participation restrictions by a majority of judges were also labelled as 'other' by both judges; these PCs are marked by an asterisk in table 3.

Discussion

This study examined how people with mobility disabilities represent those disabilities and whether those representations were consistent with theoretical models used to understand the causes and correlates of disability. People with mobility disabilities associated with osteoarthritis generated a variety of elicited PCs to distinguish between four activities used in measures of mobility disability. These PCs were found to be consistent with theoretical constructs from psychological and medical models of disability. There was little evidence of elicited PCs outside the three models investigated.

The PCs, as elicited, are consistent with other evidence of disability representations. Existing research literature has identified fear of falling and endurance factors, such as fatigue and shortness of breath, as important components of the representation of the causes of mobility disabilities in a community sample of older women [24]. Further, the PCs related to perceived risk of falling, such as fear of falling, dizziness and balance are consistent with the observation that fear of falling is prevalent in older people [25-27]. Fear of falling may be especially important because it is this perception rather than falling per se that relates to functional decline and admission to nursing homes [26].

However, the observation that only a minority of participants used pain as a discriminator was unexpected and may indicate either that pain is not used in personal representations of mobility disability or it is not used in the context of the

elicitation interviews. Previous work demonstrated osteoarthritis patients show a near universal level of agreement that pain is a core descriptor of the condition [28], and pain is the primary indicator of impairment in osteoarthritis [29,30]. Pain also acts as an index of the seriousness of osteoarthritis in patients and was the most frequently cited cause of locomotor disability in a community sample of older women [24,31]. Based on this body of work and the fact that participants were recruited into the study based on both their pathological and mobility status, pain was expected to be used frequently to distinguish between the activities.

There are a number of possible explanations of why a majority of participants did not use pain as a discriminator. First, the pervasive nature of the experience of pain in osteoarthritis may negate its discriminative properties. Alternatively, activities in general may not be evaluated relative to impairment or disease related cognitions, or such cognitions are unavailable for use in the context of the elicitation setting. However, participants did employ other impairment PCs related to their joints, for example, joint stiffness and joint movement were used by 5 participants to discriminate between the activities. These data suggest that activities were discriminated using osteoarthritis disease or impairment related PCs. Thus, the relative lack of use of pain PCs occurred because either pain was not an adequate discriminator or pain PCs were not available for use in the current context, i.e. a face-to-face elicitation interview carried out in the participant's own home. It is entirely possible that pain PCs would be available in other contexts, for example a medical consultation.

In addition, the positive framing used in the current study, may have elicited different PCs from a medical or deficit based frame of reference. Previous studies focussed

on either the representation of osteoarthritis itself or the causes of disability, whereas the focus of the current study was on performance of an activity. Participants were not asked about their activity limitations or their disease state, therefore, neither a deficit nor medical model were evoked by the elicitation study. Rather, participants were asked about their mobility related behaviour which may have reduced the use of disease related PCs such as pain. Disability measures often require patients to report on limitations in their ability to perform particular activities and consequently, deficit-based representations may shape their responses. Evidence indicates that question framing can influence self-report in general [32], and in particular, positive and negative framing has been shown to influence symptom reporting and subsequent self-report measures of health status [33,34]. It is possible, therefore, that if disability measures employed positively framed questions they would elicit a different pattern of response. This possibility may have important consequences when clinical decisions are based on deficit type disability measures.

The elicited PCs were judged to correspond to the constructs in both the psychological and medical models, and there was consistency in the labelling of individual PCs, with majority agreement evident in the choice of label for 24 and 27 of the 34 PCs in the psychological and medical construct labelling tasks respectively. In addition, the consistent use of pairs of constructs from the TPB and SCT to label the same PCs reflects the agreement in the literature that redundancy or overlap exists between the two models. Numerous studies have revealed factor complexity between measures of perceived behavioural control (TPB) and self-efficacy (SCT) and that measures of self-efficacy can empirically substitute for perceived behavioural control within the theoretical framework of the theory of planned behaviour [35-39]. Likewise, the similarly between outcome expectancy (SCT) and

attitude (TPB) has been highlighted [40]. This construct overlap was identified by the judges in the pattern of construct pairing in which perceived behavioural control was frequently paired with self-efficacy and attitude with outcome expectancy.

The consistency in the use of theoretical constructs as labels was also reflected in the mean confidence ratings which were all above 50%. However variation in the confidence ratings was evident, but an examination of the data revealed this variation was primarily due to lower confidence ratings associated with the assignment of construct labels for which there was no majority agreement. That is to say, when a majority of judges labelled a PC with the same construct, the confidence rating for the use of that construct was higher than when it was used to label a PC by a minority of judges. Thus, the low confidence rating associated with the assignment of self-efficacy, impairment and participation restrictions reflects the fact that they frequently occurred as minority labels.

The ICF, however, is a simple framework which attempts to make clear distinctions between the three core constructs; consequently the frequent use of multiple medical constructs to label the same PC cannot reflect a shared underlying theoretical concept. Rather, the use of multiple labels in the context of the ICF may put the separation of the theoretical constructs in doubt. Indeed, psychometric analyses have highlighted the difficulty of developing distinct measures of the three constructs [29]. Alternatively, it may indicate the lack of a clear relationship between the constructs in the ICF and the elicited PCs; however this was not reflected in lower confidence ratings for the ICF constructs. Nevertheless, the more frequent use of the 'other' category in the medical model task may be suggestive of a lack of a clear relationship between the PCs and the medical constructs. This may be less of an

issue in the case of the relationship between the impairment construct and the elicited PCs because the ‘other’ category was not used by both judges for PCs on which there was majority agreement for the use of impairment as a label. That said the use of the ‘other’ category did not show a pattern that could be used to identify alternative candidate models.

Taken together, the data from the judgement task revealed that the PCs used by people with disabilities are consistent with both psychological models and the ICF. Further, all of the elicited PCs could be labelled with constructs from either the psychological or medical models or both. This suggests that the participants in the study did not employ alternative models of their disabilities. The judgement tasks also revealed that some PCs were consistent with both psychological and medical models. Six of the PCs labelled by a majority of judges as outcome expectations were subsequently labelled as impairment and three as activity limitations. Consequently the use of both psychological and medical models to interpret the elicited PCs provided a more detailed understanding of those PCs than either model applied alone. This suggests that there is no reason, at the conceptual level, that psychological and medical models cannot be employed in an integrative manner and there is something to be gained by integrating the models. However, the consistency between the elicited PCs and the theoretical models cannot be interpreted as an indication of the ability of the models to explain mobility disability in people with osteoarthritis, which is an empirical question requiring a larger scale quantitative study.

When applied to the rehabilitation context the current study suggests that a shared understanding of mobility disability between client and health professional is easily

achievable and there may be some benefit from an explicit exploration of the client's representation of their disabilities. If the health professional has a full and accurate picture of how their client understands their disabilities this information can be used to inform therapy. For example, rehabilitation goals that are consistent with a client's personal understanding of their disabilities may be preferable to those that are inconsistent with that personal understanding. Further, there may be some merit in maintaining an explicit discussion of the client's representation of their difficulties, especially on transition from a hospital or clinic setting to community based rehabilitation because the individual's environment may affect that representation. For example, the clinical environment may act to strengthen the impairment content of the representation but on discharge into the home setting the activity or social aspects of the representation may be strengthened at the expense of the impairment based content.

The current study is limited by the small number of participants and the manner in which they were identified as well as the limited set of activities investigated. However, individuals were identified by disability, rather than by diagnosis alone, and the numbers investigated generated a large amount of data describing the quality of their representations of mobility behaviours. Replication of the methods with another sample of participants and activities would aid generalisation of the results. Similarly, a replication employing judges with different professional expertise or personal experience would also be of value. The interpretation of the PCs in the current study will, in part, reflect the health psychology expertise of the judges.

In conclusion, the results show that individuals with activity limitations conceptualise activities in a manner that is compatible with both psychological and medical models.

At a practical level, this ensures adequate communication in contexts where the medical model is relevant, e.g. clinical contexts, as well as in everyday conversation about activities and behaviours. At a theoretical level, the results suggest that some accommodation between medical and psychological models of disability may be possible and testing combined models would be of value. Where different theories have similar constructs, everyday language would appear to tap the shared elements.

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Table 1: Theoretical Constructs And Their Definitions

Construct	**Definitions and their sources**
Attitude	Degree to which a person has a favourable or unfavourable appraisal of a behaviour[16].
Goal	The purpose toward which an endeavour is directed; an objective (dictionary.com)
Intention	Motivation, conscious plan or decision to exert effort[16].
Outcome expectancy	A judgment of the likely consequences of performing a specific behaviour[40].
Perceived behavioural control	Perception of the ease or difficulty of performing a behaviour[16].
Self-efficacy	Perception of one's capabilities to organize and execute courses of action required to produce given attainments[40].
Sociostructural factors	Perceived facilitators or obstacles to performing a behaviour[40].
Subjective norm	Perception of the likelihood that important referent individuals or groups approve or disapprove of performing a particular behaviour[16].
Impairment	Problems in body function or structures such as significant deviation or loss. **Body functions** are the physiological functions of the body systems (including psychological functions). **Body structures** are anatomical parts of the body such as organs, limbs and their components[7].
Activity limitations	Difficulties an individual may have in executing activities. **Activity** is the execution of a task or action by an individual[7].
Participation restrictions	Problems an individual may experience in involvement in life situations. **Participation** is the involvement in a life situation. [7]
Other	Use this category for any PC that you judge to be entirely incompatible with any of the constructs

Table 2: PCs Elicited From Each Participant

Ppt	N° of PCs (unique PCs)	Elicited PCs
1	9 (4)	balance, difficult, effort**, exercise**, **pace, relaxing**, stick, stiff, **strain**
2	6 (2)	bend, difficult, **hurts**, **speed**, stick, support
3	7 (2)	joint movement, comfortable, **concentration**, **dizzy**, effort, fall, support
4	4 (0)	effort, fall, painful, support
5	6 (1)	easy, effort, fall, **safe**; support, tiring
6	6 (0)	easy, effort, fall, painful, support, tiring
7	7 (2)	balance, **duration**, easy, fall, **speed**, stiff, tiring
8	5 (2)	**breathless**, **control**, easy, effort, painful
9	3 (0)	effort, fall, support
10	4 (2)	easy, effort, **strenuous**, **stressful**
11	6 (0)	bend, easy, hazardous, painful, support, tiring
12	4 (0)	bend, easy, falling, support
13	7 (3)	comfortable, effortful, **energy**, **exertion**, **frequency**, hazardous, joint movement

Ppt=participant; Unique PCs are listed in **bold** typeface.

Table 3: Theoretical Constructs Used To Label The Elicited PCs

	Construct	N° of judges using label	No of PCs labelled	conf[a] (sd)	PCs assigned to each construct[b]
Psychological Model	Outcome Expectancy	6/6	26	67 (18)	Hazardous; Hurts; Is relaxing; Likely to fall; Makes me breathless; Makes me feel dizzy; Makes me stiff; Painful; Possibility of falling; Requires lots of joint movement; Tiring; Will not fall;
	Attitude	6/6	25	62 (17)	Feel safe when doing this; Is relaxing; Is straining; Painful; Strenuous; Stressful; Tiring
	Perceived Behavioural Control	6/6	13	62 (19)	Comfortable to do; Effortful; Is easy
	Self-Efficacy	5/6	14	55 (20)	Can control movement; Can do at my own pace; Can do for a long time; Can do quickly
	Sociostructural factors	4/5	19	73 (19)	Need physical support; Needs a walking stick
Medical Model	Impairment	10/10	22	54 (23)	Can control movement; Hurts; Makes me breathless; Makes me feel dizzy; Makes me stiff; Painful; Requires fine balance; Requires lots of joint movement
	Activity limitations	10/10	34	65 (18)	Can do for a long time*; Comfortable to do*; Effortful*; High exertion; Is easy*; Is exercise; Is straining; Likely to fall; Need physical support; Possibility of falling; Requires effort*; Requires lots of energy; Strenuous*; Will not fall
	Participation restrictions	9/10	31	57 (22)	Can do quickly*; Feel safe doing this; High exertion; Needs balance; Requires concentration

[a]mean confidence rating for each theoretical construct; [b]only PCs for which there was agreement by a majority of judges are listed. A majority was ≥4 for the psychological constructs and >5 for the medical constructs. *PCs that were labelled as 'other' by both of the two judges who used the 'other' category label.

Appendix: The 34 Non-overlapping PCs Used In The Judgement Task

PC	**PC**	**PC**
Can control movement	Is exercise	Possibility of falling
Can do at may own pace	Is relaxing	Requires concentration
Can do for a long time	Is straining	Requires effort
Can do quickly	Likely to fall	Requires fine balance
Comfortable to so	Makes me breathless	Requires a lot of energy
Do with high frequency	Makes me feel dizzy	Requires lots of joint movement
Effortful	Makes me stiff	Strenuous
Feel safe when doing this	Need physical support	Stressful
Hazardous	Need to bend my knees	Tiring
High exertion	Needs a walking stick	Will not fall
Hurts	Needs balance	
Is easy	Painful	