Effective mobility framework: A tool for designing comprehensive O&M outcomes research

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In orientation and mobility (O&M) outcomes research, the concept of mobility has become narrowed to what can be captured with existing measures and methods. However, travel speed and contact tallies have not provided convincing evidence of functional changes resulting from O&M programs or such vision restoration treatments as retinal prostheses. This study used grounded theory methodology to develop a new understanding of mobility from expert opinions, including O&Mspecialists (n=15) and adults (n=40) with advanced retinitis pigmentosa. The Effective Mobility Framework includes the elements of Utility, Access, Orientation, Interdependence, Self-regulation, Efficiency, and Pleasure representing a more comprehensive understanding of O&M outcomes than previously used. The Framework highlights the importance of mixed methods data collection and the need for new types of ordinal measure in researching functional outcomes.

Background

Orientation and mobility (O&M) can be understood from two perspectives. On one hand it refers to the professional action of O&M specialists on their clients' behalf and most of these clients have low vision or blindness. According to a number of professional texts, O&M intervention gives priority to safety, efficiency, independence, and gracefulness in travelling to a desired destination (Hill & Ponder, 1976; Weiner, Welsh, & Blasch, 2010). From the clients' perspective, O&M is holistic, encompassing such everyday actions as moving around the kitchen to make a meal, hanging out the washing, going to work, or shopping. Holistic O&M programs are targeted to the individual client's needs and might involve practical training in visual efficiency, selfprotection, road safety, mobility aid use, decision making skills, or social access, but in doing so can address any specific issues that might undermine the client's travel confidence (Deverell, Taylor, & Prentice, 2009).

O&M outcome measures are needed to demonstrate the ways that O&M training impact the everyday lives of people who receive services. The other context that calls for evidence of O&M outcomes is the developing field of vision restoration treatments, for example, retinal prostheses (Schneck & Dagnelie, 2011).

The assessment of functional vision and associated performance can be approached from two directions: parts-to-whole, and whole-to-parts (World Health Organization, 2001). Eye care professionals assess the structure and function of the eye, and this parts-to-whole assessment contributes towardsanunderstandingoffunctionalvision. To date, some O&M outcomes research has tended to use this parts-to-whole approach. Travel speed and contact tallies are used as performance indicators on travel routes that are prescribed by researchers, either in laboratory-based or real world environments (Geruschat, Bittner, & Dagnelie, 2012). However, these measures and methods have not yet produced convincing evidence of the functional value of vision restoration treatments or O&M training, even when participants have reported gaining benefit from the intervention they received (Virgili & Rubin, 2010).

In contrast, an O&M specialist tends to work whole-to-parts, beginning assessment by considering the client's range of activities and participation in the wider community before identifying the micro elements which impact performance. This assessment process generates abundant qualitative data about functional vision and O&M, but these data are difficult to reduce and compare between unique settings, or pre-post intervention. Some degree of standardisation and measurement is needed to facilitate comparison and analysis of data and the challenge is to introduce standardisation without compromising the essential nature of O&M outcomes (Durward, Baer, & Rowe, 1999).

The disjunction between the research designs used to evaluate O&M outcomes to date, and clients' real-world O&M experiences, suggests that researchers need to consider how O&M is defined and how best to capture each client's unique experience of O&M, and then explore alternative ways of measuring O&M performance.

O&M action is complex, and is manifested differently according to each person's unique vision, abilities, circumstances, lifestyle priorities, and choices (Orientation and Mobility Association of Australasia, 2013). Geruschat et al. (2012) proposed that benefits from a retinal prosthesis might be more evident in orientation than mobility, but the very first text documenting O&M techniques noted that when considering performance. functional mobility and orientation can be difficult to separate (Hill & Ponder, 1976). Physical locomotion from place to place helps to build an understanding of the temporal or spatial relationships between significant objects. In turn, an understanding and recognition of surroundings can foster more confident movement. Thus, O&M outcomes research might be approached from the perspective of either orientation or mobility, but needs to encompass both because of the reciprocity between the two.

Physical action is easier to observe than the cognitive processes involved in orientation, making mobility a more tangible construct to assess. The International Classification of Functioning, Disability and Health (ICF) considers mobility both at the micro level of body structure and function including: joint mobility, muscle power and tone, and involuntary movements – as well as the macro level of activities: lifting and carrying objects, fine hand use,

walking, moving around using equipment, using transportation, and driving (World Health Organization, 2003). However, Metz (2000) has identified elements of mobility that also incorporate psychosocial factors and participation: "(1) Travel to achieve access to desired people and places (2) Psychological benefits of movement - of 'getting out and about' (3) Exercise benefits (4) Involvement in the local community (5) Potential travel, or knowing that a trip could be made, even if not actually undertaken" (p. 150). Metz's definition is important since it acknowledges that the traveller is always located in a specific social context, whether other people in the environment are nearby or far away (Robson, 2011). However, orientation is a notable omission from both the ICF and Metz definitions of mobility.

The O&M profession both in Australia and elsewhere does not seem to use any established measures of orientation skills. Instruments such as the Rey-Osterrieth Complex Figure Test (Bennett-Levy, 1984) and the Wechseler Block Design subtest (Wechsler, 1976) were both established many years ago and continue to be used in neuropsychology assessments, but both instruments rely on vision to assess spatial perception. In O&M, when a person has poor spatial skills and tends to get lost easily, vision can be used to find landmarks or signs, to follow other pedestrians, or find by-standers to help. However, vision is not crucial for someone with strongly developed spatial skills to gain and maintain a sense of orientation during travel (Golledge, 1999). Other non-visual information about the environment can serve just as well to detail the traveller's mental map. Such aspects of low vision or blind mobility as spatial cognition are not necessarily obvious to people who can see (Mettler, 2008) and this makes them more challenging to assess. Tests of spatial cognition and orientation skills which do not require vision are needed to gain a fuller understanding of the relationships between orientation, vision, and mobility in O&M performance.

Approaching O&M holistically means considering participation not just specific activities. Here the notion of "life-space" is pertinent; this notion was proposed in 1936 by Kurt Lewin, who was working in the field of gerontology. Life-space refers to the geographical area a person occupies in the course of daily living and can serve as an indicator of activities and participation (Baker, Bodner, & Allman, 2003). An older person's life-space might be limited to his aged care home and a weekly outing to the local shops, whereas a middle-aged person's life-space might be much broader because of her career-related travel interstate or overseas

Loss of mobility reduces opportunity for participation in social activities and work, volunteering, shopping, healthcare visits, and faith-based activities (McCarthy, 2009). Contraction of a person's physical and social life-space can lead to social isolation, loss of status and confidence, loss of selfworth, depression, and declines in physical wellbeing (Baker et al., 2003; Horowitz, 2004; Oxley & Charlton, 2009; Oxley & Whelan, 2008). O&M intervention seeks to arrest this contraction of life-space and, if possible, to expand a client's viable travel options, while also teaching and testing the physical and cognitive skills which are needed to make this travel possible (Deverell, Scott, Battista, & Hill, 2014). Vision restoration treatments seek to serve a

similar purpose in expanding life-space and, by association, quality of life.

When investigating whether or not new travel skills or life-space expansion have been achieved through O&M training or vision restoration treatments, a clear understanding of what is involved in O&M, to know what to measure is needed. The aim of this study is to 're-scope' "mobility" from the perspective of both O&M specialists and clients, in order to prompt fresh thinking about the design and selection of tasks and measures which might capture O&M outcomes.

Methods and findings

At Bionic Vision Australia (BVA), the clinical research team had the challenge of designing O&M research that could demonstrate the functional impact of BVA's prototype retinal implant (Ayton et al., 2014). The team wanted to capture comprehensive data about O&M action, even if there were areas of performance that were not easy to measure. Prior to developing a research protocol, grounded theory methodology (Strauss & Corbin, 1998) was used to conceptualise effective mobility. Grounded theory is constructed from raw data through a process of constant comparison, thus methods and findings are combined in this report.

The term "effective" was carefully chosen through discussion between BVA team members. Possible seed questions for the study were then piloted with a convenience sample of colleagues and acquaintances (n=13). The research team considered that the term "functional" relates to what people *can* do, what works and what is useful, and this is preferable to the deficit thinking

typically associated with "suffering vision loss." However, functional performance might be achieved inefficiently or might be only partially effective. In relation to the bionic eye, the BVA research team wanted to consider and measure not just what people do, but what works really well and might constitute success.

First, the team undertook an enquiry with O&M specialists (n=15) to scope effective mobility, then used these ideas to shape a functional vison research protocol known as LoVADA - the Low Vision Assessment of Daily Activities. The LoVADA protocol was piloted with adults (n=40) who had advanced retinitis pigmentosa (<6/60 visual acuity or <10° visual fields). LoVADA will be described in detail elsewhere. In brief, the protocol includes three levels of route travel complexity, a visual integration task using guided travel, an orientation task involving free-roaming mobility, and a free-walking mobility task undertaken without a mobility aid which evaluates visual landmarking, straight line travel, and reorientation. These tasks generated multiple qualitative, quantitative, and graphic data streams, and included the semi-structured interview question: "What do you think makes your mobility effective?"

The draft categories that were derived from initial consultation with O&M specialists were then revised using qualitative data from the pilot LoVADA study. Two streams of qualitative data represented the perspectives of the research team as well as participants' ideas about effective mobility.

This study was conducted with the approval of the Human Research Ethics Committee at the Royal Victorian Eye and Ear Hospital, Melbourne, and in accordance with the Declaration of Helsinki. Participants gave informed consent to their participation.

CONSULTATION WITH O&M SPECIALISTS

At the International Mobility Conference (IMC14) in New Zealand, February 2012, the O&M specialist and two optometrists from the BVA clinical research team presented an open forum to investigate notions of mobility.

O&M specialists (n=15) from Australasia, UK, and Europe were asked, "What do you think is involved in effective mobility?" Participants were encouraged to consider O&M clients they had worked with, as well as their own mobility experiences, both near home and when travelling abroad, and then independently write at least five responses.

Nominal group technique (Robson, 2011) was used to share these notions – each person offered one of their ideas in turn, continuing around the group until all ideas were exhausted. Participants generated 89 responses to the seed question which were entered into an Excel spread-sheet displayed on a screen during the workshop. The group clarified and discussed responses as they were offered, but participants were not asked to reach any consensus about what constitutes effective mobility.

INITIAL ANALYSIS

After the workshop, the responses to the seed question were coded using an Excel spreadsheet. The initial coding was relatively quick because respondents had already distilled their ideas down to single words like "natural" or phrases like "how you fit with the environment around you (e.g., left hand side vs right hand side on escalators)". Nevertheless, several passes through the list of responses were necessary.

In the first pass, most items were coded as either egocentric or allocentric according to whether the effectiveness of mobility seemed to relate to the person's body, cognition, and such personal skills as "planning" (egocentric), or to such broader social or environmental factors as "user-friendly built environment" (allocentric). However, some items incorporated both egocentric and such allocentric elements, so effective mobility means "autonomy, but no car (being unable to drive) means that freedom and options are more limited" or it requires "social awareness - something being a hindrance for others." This combination prompted other approaches to analysis.

Using the original Excel spreadsheet from the workshop, multiple columns were used to code each item from different perspectives. Consideration of participants' responses stimulated several questions during coding that were used to re-examine the data. This process of constant comparison is characteristic of Grounded Theory methodology. The questions included: "Is this item impacted more by internal or external factors? What is the relationship between physical, psychological, and social elements in mobility? Where is the locus of power in relation to this item? How does this item fit with a western emphasis on independence in relation to O&M? Who benefits from this aspect of mobility and how is the benefit manifest? What is the relationship between conscious intention, unconscious action, and effectiveness in relation to this item?" This process of constant comparison occurred during multiple passes through the data, and helped to identify further relevant language and codes.

The Excel facility of sorting columns A-Z meant the original items could be readily reordered according to the codes in a column, and their congruence considered. Categories were sought for out-lying or single-construct items. Where there were three or four items with the same code, a decision had to be made about whether or not this constituted a category in its own right, or whether these items might fit into another category.

DRAFT CATEGORIES

Eight draft categories resulted from this initial coding process:

- 1. *Utility* a sense of having goals or needs, and being able to meet them
- 2. Access to the environment, to information, expertise, and essential equipment
- 3. *Choice* about resources, destinations, travel routes, environments, mobility aids, and level of in/dependence
- 4. Planning and decision making skills
- 5. *Spatial orientation* including awareness of sensory and landmark information which informs travel decisions
- 6. *Social skills* the cultural capital to understand and use the social environment to connect effectively with others
- 7. *Self-regulation* skills which impact on confidence, attitude, motivation, and resilience
- 8. *Travel efficiency* using energy and resources to meet needs easily and comfortably.

These eight draft categories revealed how much more there was to consider beyond travel efficiency when designing O&M outcomes research. Decision-making, sensory integration, and self-education were clearly part of the *process* of O&M action. These essential processes meant that opportunities to make authentic choices and responses needed to be incorporated into research tasks, and measures needed to capture the cognitive and social processes involved in effective travel, not just the mechanical actions of the body.

These draft categories drawn from the experience of O&M professionals were sufficient to inspire the design of new tasks and measures in the LoVADA protocol. However, the categories still needed to be revised and warranted by people who have daily, lived experience of low vision or blindness before they could be said to represent effective mobility from clients' perspectives.

RESEARCHERS' OBSERVATIONS

After LoVADA data collection was completed, a concept map (FreeMind software, available at http://download. cnet.com/FreeMind) was developed with effective mobility at its centre, using the eight draft categories as the first ring of ideas to build upon. Graphic mapping is a useful strategy for collating ideas and exploring their associations (mind maps), relationships (concept maps), and inferential connections (argument maps) (Davies, 2011). Incorporated into this effective mobility map were participants' travel skills observed by researchers in the LoVADA studies, as well as constructs relating to effective mobility which were gleaned during discussions between colleagues throughout the data collection process, noted in field notes and in meeting minutes.

After considering data from the research team, the *Planning and Decision Making*

category was absorbed into *Choices* which was in turn absorbed into *Self-regulation*.

Several items relating to pleasure or satisfaction had been identified in the original data-set from the New Zealand forum including "desire", "drive", "joy," and "fun" but these had been subsumed into Utility in the initial categories. However, utility can involve juggling the priorities of multiple stakeholders, whereas satisfaction is quite personal. The LoVADA participants' pleasure in effective mobility was repeatedly captured in video footage. Their faces lit up with smiles whenever they completed challenging tasks successfully. Conversely, several participants described immobilising depression the they experienced when first diagnosed with retinitis pigmentosa, and the importance to their mental health of reclaiming their mobility. Thus, a distinct category, Pleasure, was created.

The last change to the range of categories was made in relation to independence, which has historically been a priority of O&M intervention. Independence was flagged as important by a few O&M specialists, but the primacy of independence was also questioned: "Is independent travel the most effective?" There has been a shift in focus from independence to self-determination within the O&M profession in recent years which is associated with clientcentred practice (Deverell et al., 2014). This shift is not yet reflected in the O&M outcomes literature which still tends to hold independence as a central priority. When independence is interpreted as solo travel with no social contact, the independent person can simply be lonely. Even the LoVADA participants with sophisticated independent travel skills said they often preferred travelling with others, particularly to a new place. Thus, *Social Skills* and independence were incorporated into a new category called *Interdependence*.

Interdependence can be understood as a scale between solo performance involving no social contact, and actions that depend on a companion for assistance. The name of this category reflects the fact that even the most capable travellers still function in a social world which involves the give and take of embodied cultural capital and social skills (Bourdieu, 2011). Daily decisions about travel are made on the basis of circumstance and necessity (living alone or with others), capability, and social preferences. The principles person-centred of practice suggest it is not for the O&M specialist, observer, or researcher to decide that the traveller should be travelling solo if independence is contrary to the traveller's choices (Dodds, 1988). As a result it is just as important to investigate the outcomes of vision treatments or O&M training in social contexts and with accompanied travel, as it is with independent travel.

CLIENTS' COMMENTS

LoVADA participants made 55 statements in response to the interview question about effective mobility and these were analysed on an Excel spreadsheet using the same coding process used for the O&M specialists' comments. Twenty of these client statements related to *Access* (using mobility aids to move freely, and sensory strategies to gain information) and a further twenty statements were related to *Self-regulation* (e.g., freedom, planning, safety, fitness, and attitude). Surprisingly, these external/ internal interests echoed the allocentric/ egocentric codes first used to code the O&M

specialists' data set, but again, there were constructs which bridged both. For example: "If I get lost, I go to a room where someone is talking", which fitted both the Orientation and Interdependence categories. Several client statements emphasised the importance of familiarity and routine in accomplishing effective mobility. The LoVADA tasks were undertaken in an institutional environment. Participants varied in the level of practice they needed to become familiar with these less familiar research spaces, and some never gained a strong sense of orientation to the spaces during the day-long research session. The clients' responses which were coded as familiarity or routine were categorised under Orientation because orientation has to do with learning about and knowing specific locations.

EFFECTIVE MOBILITY FRAMEWORK

After the concept mapping review and analysis of client data, the Effective Mobility Framework was reduced to the following seven elements:

- Utility having meaningful goals or needs and being able to meet them using both intentional and exploratory strategies
- Access to the environment, with or without mobility aids; to information, expertise, and essential equipment; integrating sensory information in a timely way
- Orientation awareness of space, sensory, and landmark information; choosing, maintaining, and recovering direction during travel; developing familiarity and routines
- 4. Interdependence operating autonomously, connecting effectively with

others, and making informed choices about whether to travel in company or alone

- 5. *Self-regulation* investigating resources and options; planning and making decisions; using self-talk effectively; learning from experience; building flexibility, confidence, and resilience; maintaining safety, skills, and fitness
- 6. *Efficiency* moving easily, naturally, safely, and comfortably; minimising fatigue
- 7. *Pleasure* experiencing desire, motivation, fun, and joy in the context of exploration and travel.

Discussion

This study produced a new tool - the Effective Mobility Framework - through collaboration with international O&M specialists at an international conference and people with very low vision resulting from advanced retinitis pigmentosa. The Effective Mobility Framework includes the elements of Utility, Access, Orientation, Interdependence, Self-regulation, Efficiency, and *Pleasure*. This is a conceptual tool rather than a measurement instrument. which expands the dimensions of functional performance that might be considered and measured in O&M outcomes research. beyond what was previously captured by measuring speed and contacts in route travel tasks. The Framework informed the design of a centre-based functional vision research protocol, and has potential application to research which is designed to evaluate vision restoration treatments or O&M programs, whether in a centre-based setting or in participants' more familiar life-space.

The breadth of the Effective Mobility Framework increases the chance of capturing data about the benefit of selected interventions, particularly when using embedded mixed methods (Creswell & Plano Clark, 2011) for data collection. However, the Framework also presents O&M researchers with some significant measurement challenges.

When investigating human performance, researchers' observations of the participant and interpretation of participants' comments are inevitably influenced by their own professional and cultural filters (Dillon, 1991). In qualitative research disciplines, researchers are encouraged to identify and bracket their own biases, then seek to be as transparent as possible about these influences when reporting findings (Curtin & Fossey, 2007). These interpretative processes mean that measurement of human performance can never be viewed as solely objective (Robson, 2011) and the selection of performance measures needs to be warranted with individual participants' comments about their own O&M priorities. Thus, credible O&M outcomes research needs to generate both qualitative and quanititative data, and analyse the two data streams together so that measurement data about a client's O&M outcomes can be considered meaningful to clients.

Measurement depends on there being stable, universally relevant constructs to measure. The paradox of this study is that in seeking to identify common elements of effective mobility, O&M specialists in the study emphasised the importance of respecting clients' unique goals and priorities: "effective mobility is different at different life stages" and "different for every person." For this reason, researchers investigating O&M outcomes would be misguided in seeking to develop a single "gold standard" research protocol. Functional performance in O&M essentially defies standardisation and the client needs to be responsive to the individual demands of his or her lived environment.

Researchers investigating 0&M outcomes are thus faced with the reality that cohorts with common visual status and common O&M characteristics are likely to be quite small. Rather than an expectation of developing gold standard methods, a multiplicity of methods and measures is needed that can equip researchers and clients to capture whatever changes in O&M outcomes are relevant to an individual client. In this light, the Effective Mobility Framework should be regarded as a tool to facilitate more comprehensive research design and data generation, rather than a rigid research curriculum where every element must be measured with every person.

Researchers are encouraged to conduct a pilot enquiry with the target cohort to identify the elements of the Framework where benefits of the selected intervention seem most likely to be apparent before selecting or developing relevant measures. This approach is inverse to previous research that has built research tasks around the few existing measures. Interestingly, the only mention of speed in the study was from a client who identified the need to be adaptable to the context: "going slow and concentrating if less familiar; faster if I know the area or feel safe."

The effective mobility concept map identified some constructs which are tangible and easy to measure. For example, it is obvious in the *Utility* category whether a person has arrived at the intended destination or achieved a chosen task. However, many tacit psychosocial elements, for example, resilience, pleasure, anxiety, or comfort call for further qualitative investigation before researchers can understand the best way to approach their measurement in the context of O&M action. Rather than leaving these difficult-to-measure elements out of the research design, the team recognised the value of capturing qualitative data about difficult constructs in the form of video. noted observations, a written record of clients' self-talk, and contextual descriptions during O&M tasks, as well as more formal interview responses. These data enabled the team to further consider and develop measures that are meaningful to participants, not just to researchers.

Ordinal scales with clearly defined increments were trialled in the LoVADA protocol and showed some promise as a viable approach to measuring functional performance. These scales enabled multiple behaviours of functional interest to be incorporated into a measure, so that the integrated nature of functional performance could be captured holistically. For example, attempting to isolate and measure body positions, facial expressions, confidence, tension, social self-monitoring, and socially invasive behaviours was a daunting task, yet these constructs combined neatly into a posture/kinesics scale which eliminated the need for extensive description. Several performance scales were developed in collaboration with clients during the LoVADA study and as such capture constructivist data rather than the singular subjective opinion of self-report generated with Likert Scales. The value of each level on an ordinal scale is not consistent and

Stevens (1946) who wrote the seminal paper on measurement scales noted that this inconsistency limits the statistical analyses which can be employed with ordinal data. The performance scales developed in the context of the LoVADA protocol will be reported in detail elsewhere.

The LoVADA pilot demonstrated the usefulness of the Effective Mobility Framework in directing the generation of rich data about O&M performance using standardised tasks in a centre-based context. However, the research team learned that data about O&M performance is not necessarily the same as data about O&M outcomes. Many of the LoVADA participants commented that they performed less effectively in the unfamiliar LoVADA venues than they would function in their familiar life-space, so findings from clinical trials are not necessarily transferrable to functional contexts. It remains to be seen whether the Effective Mobility Framework can be used to shape O&M outcomes research in the client's life-space which better represents the clients' everyday O&M experiences.

The Effective Mobility Framework has been informed by multiple perspectives including collaboration with international O&M specialists, input from LoVADA participants, and from the multidisciplinary BVA team which included optometrists, ophthalmologists, occupational therapists, and orthoptists, in addition to an O&M specialist. The categories identified in the Framework are sufficiently broad to accommodate variations in O&M cohorts or research contexts. However, the expert groups consulted were relatively small and much of the grounded theory analysis was undertaken by one person. There may yet be constructs which have not been included, and the domains in the Framework are likely to vary in importance from one client to the next. The Framework might need further amendment as a result of feedback from people who are blind, who have a greater degree of useful vision than the LoVADA participants, or whose vision issues are congenital rather than adventitious in origin.

Understanding the relationship between mobility, orientation, and vision continues to be challenging for researchers. Orientation became a category on its own in the Effective Mobility Framework, but vision did not. Mettler (2008) suggested that people who are fully sighted can be inclined to attribute greater importance to vision in relation to O&M than is necessarily warranted. However, none of the O&M specialists in the effective mobility forum mentioned vision. O&M specialists are used to working with people who have no vision, so this group of professionals likely regarded vision as optional rather than essential to effective mobility. This view is emphasised by O&M phenomenology (Berndtsson, 2009) and demonstrated in the practice of blind O&M specialists (Ferguson, 2007). Conversely, several clients in the LoVADA pilot emphasised the usefulness of their light perception only in effective mobility, suggesting that every little bit of vision is valuable. Considerably more research is needed to understand how best to measure the process of sensorimotor integration during O&M undertaken by people with very low vision.

The Effective Mobility Framework has already proven useful in supporting more comprehensive design of O&M outcomes research in the LoVADA protocol than has previously been reported, as well as prompting the development of new measures of functional performance. The Effective Mobility Framework also opens up new possibilities for structured research investigating activities and participation within participants' more familiar life-space.

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