Evaluation of an Emotional Support Service for the Visually Impaired

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Number of tables: 2

Number of figures: 2

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ABSTRACT

Purpose. To evaluate the impact of a facilitated peer group emotional support service on visual quality of life (VQoL).

Methods. Consecutive participants in an emotional support service delivered to groups of up to 6 and facilitated by trained counsellors were recruited (n=29). The VCM1 instrument was administered to participants at the start of the service, at the end of the service, and 6 months after completion of the service.

Results. For the group as a whole, VQoL significantly improved between the beginning of the service and the end (F(1, 23) =16.43, p=.000), but was no better than at the start six months later (F(1,23)=3.60, p=.07). However, those with poorer initial VQoL showed significantly greater improvements after six months (1.74±2.21 logits) than those with higher initial VQoL (-0.12±0.71 logits) (t(23)=2.89, p=.008). The effect size of the intervention for those with poor initial VQoL was 1.10 at the end of service, and 0.92 after six months. The items which became and remained easier were feeling lonely or isolated due to eyesight, feeling sad or low due to eyesight, and feeling worried about general safety outside the home.

Conclusions. This facilitated peer group emotional support service significantly improves VQoL as assessed with the VCM1 over at least 6 months for those with poorer initial VQoL. Different interventions may be needed for those with initially good VQoL, and to improve other aspects of quality of life not influenced by the service.

Key words: emotional support; rehabilitation; visual impairment; low vision; Quality of Life;Rasch analysis

The psychosocial consequences of acquired visual loss are great, with high levels of depression [1-4] and emotional distress [5] reported. It is becoming better recognised that patients with visual impairment require not only optical rehabilitation in the form of low vision aids, but also emotional support in the process of adjusting to life as a visually impaired person [6-9].

What is not so clear is how to provide this emotional support, which is defined here as an intervention that involves attentive listening plus constructive suggestions [10]. For treating mild to severe depression in patients with chronic illnesses the United Kingdom's (UK) National Institute for Clinical Excellence (NICE) recommends a 'stepped care' model [11]. For providing emotional support specifically for people with visual impairment, suggested strategies include problem based therapy [12]. A randomised controlled trial is currently underway comparing the effect of individual problem based therapy with that of stepped care [13]. Group based self management therapies aimed at developing problem solving skills have also been suggested [14-21].

The availability of services specifically to provide emotional support to people with visual impairment in the UK is patchy. A recent survey [10] suggested that only around 67% of respondents thought that emotional support services were provided to visually impaired patients in their area through either the hospital or local authority. Nyman [8] identified 28 formal emotional support services in the UK, mostly provided in the voluntary sector. None were group based, and few had been formally evaluated.

Cam Sight is a charitable organisation offering services to the visually impaired within Cambridgeshire, UK. They offer a facilitated peer group emotional support

service to visually impaired people which had not previously been evaluated. The purpose of this study was to evaluate the impact of this emotional support service on participants' visual quality of life using a validated patient reported outcome measure (PROM). The aim was to understand the benefits and limitations of the service in order to improve this service provision, and also to provide evidence for other service providers considering providing emotional support services to low vision clients.

Methods

Service provision

The aims of the Cam Sight peer group emotional support service are to assist individuals in coming to terms with losing their sight, and to help individuals to rebuild self-confidence and work out new ways of coping, such that they are able to take up other services relevant to their needs.

The service is facilitated by staff trained in general and bereavement counselling skills and with experience of working with people with visual impairment. Participants attend in groups of up to six people. As only one group runs at any given time, the time of presentation is the principal driver to the formation of the groups, although an attempt is made to place participants in groups roughly matched in age. Groups attend for six to eight weekly sessions of three hours. The first two sessions take place on one day, and includes a meal. The purpose of this initial day is to allow each participant a chance to tell their story in an unhurried and open way, and to encourage social interaction through the refreshment breaks. An overview of the services provided by Cam Sight is also included, and discussions about topics to be covered in subsequent sessions are begun. The development and content of the subsequent

sessions is then determined by the groups. The role of the facilitators is to nurture the group and its dynamics, allowing participants to begin to explore the complex emotions that follow loss of sight in a safe and confidential environment. Participants are helped to start to overcome the fear of exposing vulnerability, to reduce feelings of loneliness and isolation associated with sight loss, to support each other, and to share fears and experiences which encourages a problem solving approach to difficulties. Commonly raised themes in the groups included dealing with the participants' own emotions, such as anger and sadness at their loss, feelings of vulnerability, and of frustration in achieving tasks. Dealing with other people's emotions brought on by the participant's sight loss was also a common theme, including the lack of understanding of visual impairment shown by other people, difficulties with family, friends and partners, and coping with withdrawal of support from people who had previously been close to participants.

Once the sessions have finished, ongoing telephone support is provided for six months on a monthly basis, or as needed, by staff who have been involved in the service delivery. Subsequent social events for participants are also arranged. One month after the end of the service, a 'coffee and cake' social is held for members of the group. An annual buffet lunch social is also held, to which members of all participating groups are invited for at least two years after completing the service.

Evaluation

Questionnaires were administered by KL, an optometrist who was not involved in service provision, and MP, a clinical psychologist who was present during the service provision. Questionnaires were administered within the first session of the service

('start' time point) and again in the last session of the service ('end' time point). These were administered in person, usually by KL but occasionally by MP. Six months after the service had completed, the questionnaire was administered again by telephone by MP ('after' time point).

The 10 question Vision Quality-of-life Core Measure (VCM1) [22, 23] (Table 1) was used for the evaluation. This was chosen as it was developed for use in patients with a broad range of conditions causing sight loss, had face validity in addressing areas related to the aims of the service, and has previously been demonstrated to represent a unidimensional scale in low vision observers [24, 25]. The questionnaire assesses visual aspects of quality of life, by asking participants to consider how often they have felt their eyesight has impacted on various aspects of their life over the past month. Responses were made on a 5 point Likert scale from 'not at all' to 'all the time', which has previously been shown to result in ordered category thresholds [25].

Participants

Most participants were referred to the service by hospital eye clinics within Cambridgeshire, with the remainder being self-referrals to Cam Sight. Before enrolling in the peer support service, an Emotional Support Worker visited each potential participant to discuss the services available, and to arrange transport.

29 subjects attended the service between July 2010 and October 2011 (16 male, 13 female; mean age 54±20 years, range 20-91 years; mean duration of visual impairment 3±2 years, range 6 months-10 years). Five subjects were not registered as visually impaired, nine were registered as Sight Impaired (SI), and fifteen were

registered as Severely Sight Impaired (SSI). The SSI group included four participants with no perception of light. Self-reported causes of visual impairment amongst the participants were diabetes (n=2), macular degeneration (n=7), retinitis pigmentosa (n=5), optic neuropathy (n=4), stroke (n=3), brain tumour (n=6) and unknown (n=2). All subjects consented to participate: 29 completed the initial evaluation, 27 completed the evaluation at the end of service provision, and 25 completed the evaluation six months after service provision. Data for all three time points was available for 24 participants.

Ethical approval for the study was obtained from Anglia Ruskin University Faculty of Science and Technology Ethics Committee. The tenets of the Declaration of Helsinki were followed, and all subjects gave informed consent to participate after the nature and consequences of the study had been explained.

Analysis

Rasch analysis [26, 27] was used to determine VCM1 person measure scores from the ordinal Likert responses using Winsteps version 3.71.0.1 [28] with a single Andrich rating scale. Rasch analysis allows questions to be weighted according to their difficulty, and results in a score in logits, where a higher person measure score represents greater ability in the parameter in question (in this case, greater visual quality of life), and a greater item difficulty means that quality of life must be greater to be able to agree with the question.

To examine changes in participants over time, Rasch analysis was first applied to data from all time points (n=81). Each item was entered once into the analysis and

associated with measures entered for each person at each time point. This analysis fixes item difficulty and forces all change into the person measure, and is described as 'stacking' of the data [29, 30]. A stacked analysis assumes that the task does not change in difficulty over time, but that the intervention employed may affect whether the task is within a subject's functional range. By evaluating the change in person measure across time points, stacked data is used to determine who benefits from a rehabilitation intervention.

Differential item functioning (DIF) was also assessed in order to determine whether different groups within the sample (e.g. based on gender, age, registration status or duration of loss) responded differently to different items within the stacked data.

To determine which items were responsive to rehabilitation, data were then 'racked' [29, 30]. Each person was entered once into the analysis and associated with measures entered for each item at each time point. Racking keeps the person measure constant across time and forces all change into the item difficulty. This analysis therefore assumes that the patient does not change, but that the intervention changes the difficulty of the items, as in the example given by Wright [29]: "I'm still the same person, but now climbing stairs is easier!" By evaluating change in item difficulties across time points, racked data is used to determine which questionnaire items are responsive to the rehabilitation intervention, and as such represents an alternative way of evaluating DIF across time points.

Both 'stacking' and 'racking' are thus relevant to measuring rehabilitation outcomes so as to determine both who benefits from the intervention, and in what way the intervention influences performance.

Results

Item difficulties and MNSQ infit and outfit values, indicating the fit of the items to the Rasch model in the 'stacked' data, are shown as the 'initial model' in Table 1. Category thresholds were ordered for all items, and person separation (2.82), item separation (4.62) and targeting (mean person measure -0.02 logits) were all acceptable [31]. However, the model was not sufficiently unidimensional [32], with a first contrast eigenvalue derived from principal component analysis of the residuals of 2.1, and MNSQ infit and outfit values for some items fell outside the acceptable range of 0.60-1.40 [33]. The analysis was therefore repeated with the elimination of the item that conformed least well to the model (i.e. the item with most extreme infit or outfit value) and the parameters reassessed. The process was repeated, until after two iterations a stable model was derived, with acceptable MNSQ infit and outfit values, which is shown as the 'final model' in Table 1. Items 4 (embarrassed) and 8 (worried vision worse) were removed. Item 4 had the lowest item difficulty in the original model, and item 8 was confusing to the four participants who had no perception of light. The 8 item questionnaire now shows acceptable infit and outfit MNSQ values, reliable person and item separations [31] of 2.73 and 4.84 respectively, and adequate unidimensionality of the scale [32] (first contrast eigenvalue of 2.0). The mean person measure is -0.15 logits, indicating that this sample has, on average, visual quality of life that is similar to that for which the questionnaire is targeted.

---Table 1 about here---

The VCM1 in its entirety has been shown to fit the Rasch model [25]. However, Lamoureux's Australian cohort was recruited from an optical low vision rehabilitation service, implying all participants had some level of residual vision, whereas four of the participants in the present study had no perception of light. Preliminary analysis of the present data anchored to Lamoureux's item difficulties indicated unacceptable infit and outfit statistics, and a lower mean person measure in our sample than in the original data set. It therefore did not appear valid to apply the item anchors derived in the previous study to the current data, and caution is suggested before using previously derived item difficulties as anchors where a questionnaire is used with different populations. The analysis presented here uses the results of the stable 8 item questionnaire detailed in Table 1.

Repeated measures ANOVA was conducted on the stacked VCM1 person measures of the 24 participants for whom data at all 3 time points was available. The mean person measures are shown in Table 2. VCM1 person measures were significantly affected by time point ($F(2, 46) = 8.60$, $p=.006$; Mauchly's test was insignificant [$chi^2(2) = 2.12$, $p>.05$] indicating that sphericity was not violated). Within subjects contrasts revealed that VCM1 visual quality of life was higher at the end of the service than it had been at the start ($F(1, 23) = 16.4$, $p<.001$), but that 6 months after the service had finished, the VCM1 scores were not significantly better than at the start ($F(1,23)=3.60$; $p=.07$).

--- Figure 1 about here ---

To examine whether some individuals benefitted from the service more than others, the change in VCM1 scores between the start of service and 6 months after service completion are shown plotted against initial scores at the start of the service in Figure 1. The data were split at the median initial VCM1 score (-0.6 logit, dashed vertical line) and the change in VCM1 score compared between those with better and poorer initial person measures. Those with poorer initial visual quality of life showed significantly greater improvements after 6 months (1.74±2.21 logits) than those with higher initial VCM1 scores (-0.12±0.71 logits) (t(23)=2.89, p=.008).

The effect size (Cohen's d) of the intervention on VCM1 scores is explored further in Table 2. For those with poorer initial visual quality of life, the intervention had a large effect (1.10) at the end of the service, which was largely retained after 6 months (0.92). For those with better initial visual quality of life, while the intervention had a moderate effect at the end of the service (0.60), this effect was not maintained after 6 months (0.13).

DIF analysis showed no notable (>0.5 logits) differences for any item according to gender, age (split at the median age of 50 years), duration of vision loss (split at the median duration of 2 years), or registration status (split to equalise groups by comparing those with SSI registration to those with SI or no registration).

--- Table 2 about here---

In order to determine which items were responsive to rehabilitation, Figure 2 shows item difficulties at all time points obtained from the racked data of the reduced model VCM1 responses. Item difficulties at the start of the service are plotted on the x-axis, with difficulties at the end of the service plotted on the y-axis with open symbols, and item difficulties from six months after the service had ended plotted on the y-axis with filled symbols. The solid line represents the line of equality, indicating no change in item difficulty between the time points. The dashed line represents a decrease in item difficulty of 0.5 logits between the start of the service and the relevant later time point. The dotted line represents a decrease in difficulty of 1.0 logit.

--- Figure 2 about here ----

For some items, there is an initial improvement in item difficulty at the end of the service which has disappeared by six months after service provision, as indicated by a position of the open symbol towards the dotted / dashed lines, but the filled symbol falling on or near the line of equality. This applies to the initially more difficult items 3 (stopped doing things), 5 (frustration) and 10 (interferes with life in general) in particular.

Other items show an improvement which is retained after six months, with both open and closed symbols falling below the line of equality. Items 2 (safety outside home), 6 (lonely or isolated) and 7 (sad or low) show retained benefits over a period of 6 months of greater than 0.5 logits.

Discussion

The stacked data show that this facilitated peer group emotional support service had a significant impact on visual quality of life as assessed by the VCM1, with more marked improvement at the end of the service than six months later. The participants who retained benefit from the service after six months were those with poorer initial visual quality of life. The racked data show that items of the VCM1 that became and remained easier following this rehabilitation were the items concerning safety outside the home, feeling lonely and feeling sad due to eyesight.

The lack of a control group is a limitation to the present study, in common with other previous studies in this area [34]. However, by comparing the results within the group of participants, the effect of the intervention can be seen to differ according to initial visual quality of life status. Additionally, the use of three time points, rather than simply before and after the intervention, demonstrates a different time course of the impact of intervention within the participants.

Those with better initial visual quality of life demonstrate an improvement in visual quality of life at the end of the intervention that was not retained after six months. This suggests that while there is a gain from the intervention in the short term, which could be described as a 'halo effect', these participants are not gaining skills that change their visual quality of life in the long term. It is possible that visual function may have deteriorated over the six months following service provision, counteracting the beneficial effects of the intervention [35, 36]. Ideally, results for this group with better initial visual quality of life would be compared to a control group of similar participants who did not receive the intervention, in order to determine whether those participants who received the intervention deteriorated less over time than those not

receiving the intervention. However it was not considered ethically appropriate to withhold the intervention from any such group. Nonetheless, the differential effects of the service provision between those with better and poorer initial visual quality of life are still evident. It may be that the benefits of the service to the participants with better initial visual quality of life are not captured by the items of the VCM1, and / or that other forms of emotional support may be more appropriate for these individuals.

On the other hand, those who have poor initial visual quality of life not only see improvements as a result of the intervention, but these improvements are also maintained over a six month period. This suggests that these participants are learning skills or coping strategies as a result of the intervention that they are able to employ to their benefit in the long term. Similar findings of improvements maintained over a period of time have been seen in other group-based self-management programmes in Europe, Australia and the United States [14-21]. A group based self-management programme for people with AMD in the United States [14,17] led to significant improvement in levels of emotional distress compared to controls (effect size 0.48), with greater improvements seen in the patients who were depressed at baseline, and with the benefits even more pronounced after six months than at the completion of the intervention. A group based health education programme for people with AMD in Sweden [15, 16, 18] showed increased perceived confidence in performing a number of daily tasks compared to controls both at 4 and 28 months after the intervention. Another group self-management intervention aimed at older adults with sight loss in Australia [19, 20] demonstrated a significant impact (effect size 0.20) on participation in life situations, which remained significant after 12 weeks.

Overall, the evidence suggests that group based programmes can be effective in supporting people with visual impairment, particularly those who are depressed or have poor visual quality of life. It is less clear whether the positive impact of the service stems primarily from the active intervention, or from the social support and friendships that some participants make from the groups. Whilst the present study was not designed to address this question, this would be useful to investigate in future research. It is also not possible from the present study to comment on the best way for groups to be structured and whether making greater efforts to group participants in similar circumstances could increase the benefits of the service.

Other factors that may have influenced what type of participants benefitted most and least from this service other than initial visual quality of life were not evaluated in this study, but could have included change in visual function over the time of the study, and the effect of other rehabilitation services received prior to or after the emotional support service. However, we have previously noted [37] that whilst the level of adjustment to visual loss is associated with depression and some aspects of personality (neuroticism and conscientiousness), adjustment is independent of the severity and duration of vision loss, and of reported difficulties in visual tasks.

In the present study, items that improved and stayed easier to agree with were feeling worried about safety outside the home (item 2), feeling lonely or isolated due to eyesight (item 6), and feeling sad or low due to eyesight (item 7). An improvement in these items fits well with the outlined aims of the service. Items 6 and 7 in particular were 'easier' questions with lower item difficulties from the outset (Table 1), which

may explain why those with better initial visual quality of life did not see a lasting benefit from the service as these questions were within their initial functional range.

Items that initially responded to the intervention, but were not maintained after six months included feeling frustrated or annoyed due to eyesight (item 5) and eyesight having stopped participants doing things they want to do (item 3). Item 5 had the highest item difficulty. It may be that peer support is not ideal to address these particular issues, and that different rehabilitation approaches are required, perhaps more specific to dealing with required tasks. It might be suggested that additional activities of daily living training should be recommended immediately after the peer group emotional support intervention. Such training may maintain reduced feelings of frustration by capitalising on the service's short term positive effects.

In conclusion, this facilitated peer group emotional support service provides improvements in visual quality of life as assessed by the VCM1 that are maintained over a six month period for those with poorer initial visual quality of life. Items of the VCM1 responsive to this rehabilitation were confidence outside the home, feeling lonely or isolated, and feeling sad or low due to eyesight. Whilst this study does not compare the effect of this intervention with any other form of emotional support, the provision of mean person measures and effect sizes at the different time points can allow comparison with other interventions using the VCM1 as an outcome measure. This study also adds to the body of evidence that group based interventions aimed at improving self-management skills are effective over a period of time.

Acknowledgements

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Figure legends

Figure 1. VCM1 person measure scores (logits) at the start of the service (x-axis) and the change in score observed 6 months after the end of the service (y-axis). Each point represents an individual. The solid horizontal line represents no change over time, with individuals above the line improving and those below the line declining in visual quality of life. The vertical dashed line indicates the median initial VCM1 score of -0.60 logits. Point A represents an individual whose VCM1 score was initially -5.6 logits, and 6 months after the end of service was +1.7 logits, representing a 7.3 logit improvement.

Figure 2. Item difficulties (logits) at the end of service (open symbols) and 6 months after service (filled symbols) are plotted against initial item difficulty. The solid line is a line of equality: points lying on this line have not changed with time point. The dashed line represents a lessening in item difficulty (improvement) of 0.5 logits between the start and the subsequent time point, and the dotted line represents an improvement of 1.0 logit.

Tables

	Initial model			Final model		
	Item difficulty (logits)	Infit MNSQ	Outfit MNSQ	Item difficulty (logits)	Infit MNSQ	Outfit MNSQ
1. How often has your eyesight made you concerned or worried about your general safety at home?	-0.76	0.91	0.91	-1.02	1.08	1.03
2. How often has your eyesight made you concerned or worried about your general safety outside of your home?	0.58	1.07	1.02	0.53	1.13	1.16
3. How often has your eyesight stopped you from doing the things you want to do?	0.57	1.40	1.41	0.53	1.35	1.35
4. Have you felt embarrassed because of your eyesight?	-0.99	1.28	1.48	-	-	-
5. Have you felt frustrated or annoyed because of your eyesight?	1.05	0.91	0.84	1.08	0.91	0.82
6. Have you felt lonely or isolated because of your eyesight?	-0.67	0.73	0.81	-0.90	0.88	1.20
7. Have you felt sad or low because of your eyesight?	-0.38	0.79	0.77	-0.57	0.95	0.90
8. How often have you worried about your eyesight getting worse?	0.09	1.33	1.36	-	-	-
9. How often has your eyesight made you	-0.22	0.61	0.55	0.37	0.71	0.64

concerned or worried about coping with everyday life?						
10. How much has your eyesight interfered with your life in general?	0.74	0.79	0.77	0.73	0.79	0.77

Table 1. Rasch analysis of the VCM1. Participants were asked to report how they had felt over the past month. Response options: 4 Not at all; 3 A little of the time; 2 A fair amount of the time; 1 A lot of the time; 0 All the time.

	Whole group	Poorer initial VCM1 score		Better initial VCM1 score	
	Person measure	Person measure	Effect size	Person measure	Effect size
Start	-0.75±1.88	-2.08±1.71		+0.40±1.03	
End	+0.38±1.88	-0.30±1.52	+1.10	+1.20±1.58	+0.60
After	-0.07±1.61	-0.42±1.91	+0.92	+0.25±1.27	-0.13

Table 2. VCM1 person measures (logits) for the three time points assessed: at the start of the service, at the end of the service, and 6 months after service provision. Means and standard deviations are given for the group as a whole, for those with initial VCM1 score poorer than the median (<-0.6 logit) and for those with initial VCM1 scores better than the median (≥-0.6 logit). Effect sizes (Cohen's d) are given for the effect of the intervention between the start and the relevant time point for the median split data.
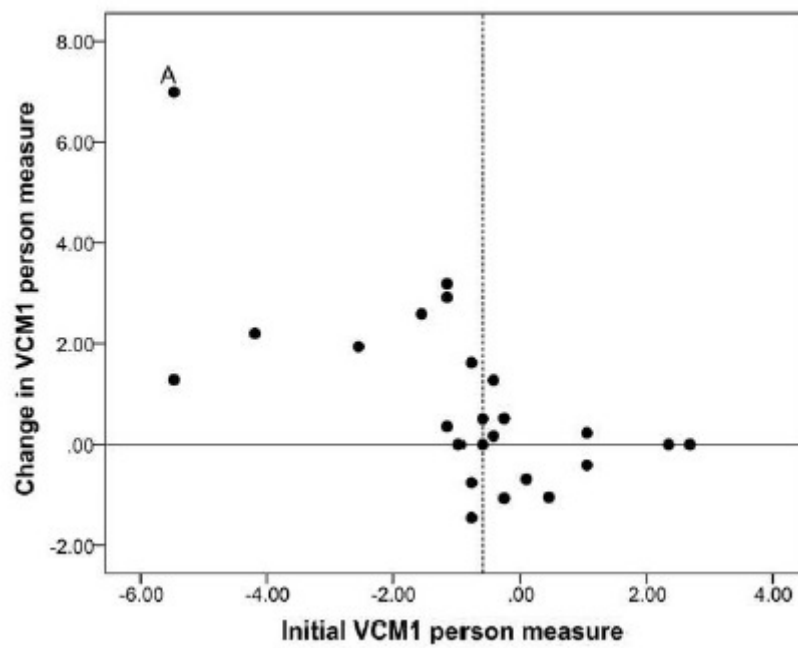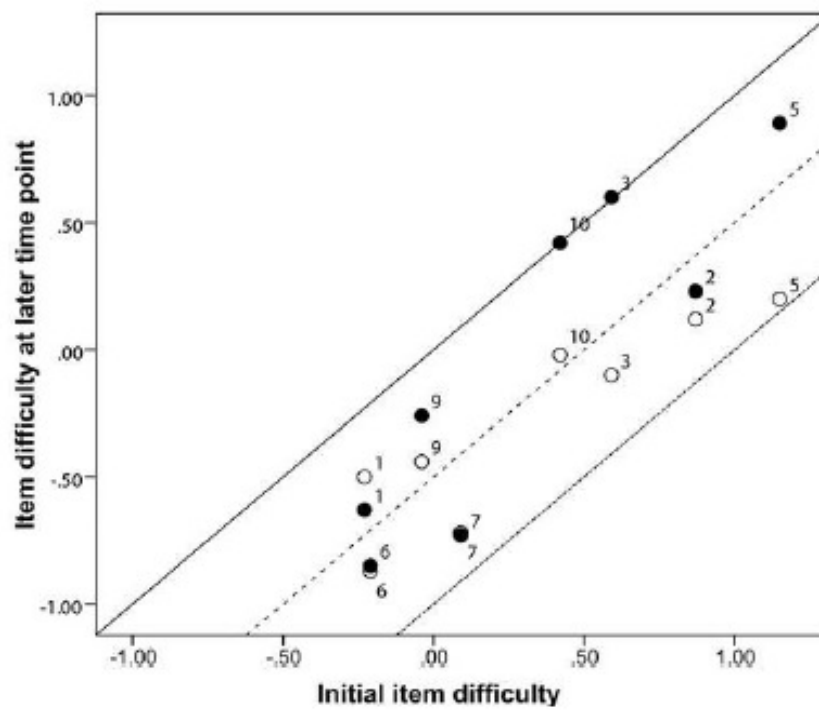
Figure 1

Figure 2