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Eyes on the prize: life goals in the context of visual disability in midlife

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Objective: To investigate implications of vision loss in midlife, identify life goals that are important to middle-aged adults and assess how vision loss interferes with goal pursuit.

Design: Cross-sectional exploratory study.

Setting: Vision rehabilitation agency.

Subjects: Two hundred and sixteen middle-aged adults with visual impairment.

Methods: Telephone interviews composed of structured and open-ended assessments of life goals (i.e. priorities, plans, or hopes people have in their lives) and goal interference due to vision loss.

Results: Across the three assessed domains, functional goals were reported most often ($N=214$), followed by social goals ($N=72$) and psychological goals ($N=28$). Among functional goals, career, daily tasks and mobility goals were identified by the highest percentage of participants. Family goals were identified most frequently for social goals, and life quality was identified most often for psychological goals. Vision-related goals occurred throughout the three domains, representing the majority of functional goals, a third of social goals, and almost half of psychological goals. Participants reported highest interference in functional and social goals and least in psychological goals. While participants reported moderate interference for most goals, markedly high interference was reported for daily tasks, mobility, independence and leisure goals. Goal identification was related to timing of onset of vision loss primarily for functional goals.

Conclusions: Findings illuminate multifaceted goals held by middle-aged adults with vision impairment and how visual disability can interfere with goal pursuits. These findings suggest that identifying clients' life goals and the vision-related interference they experience in goal pursuits may be a helpful step in vision rehabilitation services.

Introduction

Research on vision impairment and disabilities in general has focused on older adults, given that

functional loss becomes more common with advanced age. However, the study of functional loss in midlife is also relevant. As many as 15% of adults aged 45–64, representing 9.3 million middle-aged Americans, report having some type of vision problem even when using corrective lenses,¹ yet little is known about the impact of vision loss during this life stage. Furthermore, the

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prevalence of vision loss is expected to increase dramatically over the next 20 years because of the ageing of the population,² making the study of vision loss across both midlife and old age particularly important.

Midlife is the least studied period of life,³ despite the unique qualities that set it apart from other life stages. One of the main defining aspects is that individuals in midlife typically balance multiple responsibilities and life goals.⁴ Maintaining or progressing one's career is often a top goal, and many middle-aged adults feel the psychological, financial and pragmatic weight of multiple family responsibilities, such as caring for children and ageing parents simultaneously. They also often experience significant life transitions during this stage, such as raising children, having children leave home or preparing for retirement. Thus, midlife is a complicated and unique period of the lifespan that warrants further study.

In particular, an emerging body of research has indicated that visual disability occurring during midlife may have more severe ramifications because of the untimely and non-normative nature of the event.⁵ For example, prior work has demonstrated that the risk of subsequent mental health problems tends to be higher for middle-aged compared with older adults who face a visual impairment,^{6,7} and that vision loss causes more drastic life changes among younger people than older people.⁸ Furthermore, visual disability is likely to interfere with the pursuit of goals common during midlife, a period that is characterized by multiple complex goals, and when the pursuit of goals is often at its peak. Research has described life goals (i.e. priorities, plans or hopes people have in their lives) as an important motivational force that contributes to health and well-being,⁹ whereas the absence of life goals, or when there is ambivalence and conflict, is linked with various negative health effects.¹⁰ Thus, the impact of disability in midlife on an individual's pursuit of life goals is closely linked with health and well-being.

It is important to note that there is great variability across individuals in terms of how they deal with disability, with evidence suggesting that personal coping resources are a critical factor in the adaptation to visual impairment (see, for example, refs 6, 7 and 11). Broader ageing research on loss

and decline has found that the ability to adjust one's goals to what is more realistic and attainable is more adaptive than trying to pursue blocked goals (see, for example, refs 12 and 13). Using these more accommodative coping strategies has been found to be linked with better mental health in a sample of middle-aged adults who reported high, compared with low, levels of vision-related disability.⁶ Because midlife is distinguished by its multitude of life goals, the issue of life goal adjustment to accommodate one's disability should be particularly salient during this life stage.

More research is needed to better understand the experiences of middle-aged adults dealing with vision loss. Thus, the objective of this study was to investigate the implications of vision loss in midlife by identifying the life goals that are important to middle-aged adults and assessing how vision loss has interfered with and/or shaped goal pursuit. While we used a structured approach to assess life goals in some of our previous work (see, for example, ref. 14), we have more recently turned to open-ended assessments of personal goals (see, for example, ref. 15) for two main reasons: First, it has been argued that using an a priori list of goals to understand a person's goal system is likely to be misleading and restrictive (see, for example, refs 16 and 17). Thus, there has been an increasing trend toward more idiographic approaches to capture specificity, concreteness and ecological validity of individuals' goals. Second, the open-ended assessment of important personal goals seems best suited for the research presented in this paper because so little is known about the life goals of its study population. With an open-ended approach, we can gather specific information about what exactly someone was trying to accomplish in addition to determining the general life goal domain (e.g. career).

Past research has found that the functional aspects of living (e.g. personal care and finances) and relationship-related goals (e.g. partner, family) are a top priority for young adults with vision impairment, and that they are more frequently weighted as extremely important than psychological goals (e.g. life philosophy and spirituality).¹⁴ Thus, we expected functional and social goals to be identified more than

psychological goals. We also expected that vision loss would have the most interference with goals in these two domains. Furthermore, we predicted that the content of reported goals would include a mixture of goals that are vision-related (i.e. goals that focus on adapting to the challenges of vision impairment in achieving particular tasks) and goals that are not vision-related. In addition, we expected that certain goals would be unique to individuals with a visual impairment because of the particular problems they may have as a result of their disability, while other goals may be typical for midlife, such as career and family goals. Past studies have shown that vision loss has a wide-ranging impact on life goals (see, for example, ref 18), so we expected that even some of the goals that seem typical for middle-aged adults would actually be related to vision (e.g. shifting one's career focus to jobs that can be managed more easily without normal visual ability). Finally, we explored whether the type of goals reported would depend on the timing of vision loss onset (during or before midlife).

Methods

Participants for this cross-sectional study were recruited from a pool of 510 middle-aged (age 40–64) adults with vision impairment who had been first-time applicants at a vision rehabilitation agency serving the greater New York metropolitan area. All participants were experiencing significant visual impairment. Other criteria for inclusion were: age of onset of vision impairment 18 years or older, community dwelling, fluency in English and absence of cognitive or hearing deficits that could interfere with the telephone interview.

Of the pool of 510 potential participants, 90 were ineligible (35 were non-English speaking, 6 were cognitively impaired, 3 were hearing impaired and 46 had onset of vision loss prior to 18 years of age); for 92 potential participants, we were unable to establish eligibility because we never reached them; 3 were deceased, 41 would not schedule and 57 refused to participate. The calculation of our response included: those for whom we were able to establish eligibility, and of those, participants, refusals, and those who would

not schedule within the field period (considered passive refusals). We had 227 participants and 98 refusals (direct and passive refusals), resulting in a response rate of 70% (participants/participants + refusals). Eleven participants did not complete important core elements of the interview. Therefore we later decided not to use these interviews, resulting in a final sample size of $N = 216$.

Data were collected by trained research assistants through phone interviews that lasted approximately 30 minutes; all participant responses were documented on paper. The study procedures and materials were approved by the institutional review board of the agency and participants were asked for oral consent after being read a form outlining details of the study procedures, potential risks and benefits, and the use of data.

The interview included questions on basic sample characteristics (e.g. age, race, education, employment status), and vision-specific characteristics (i.e. self-reported onset of vision-related functional problems). Furthermore, the Functional Vision Loss Scale, a 15-item index, was used to assess whether or not difficulty is experienced in specific functional areas (e.g. reading newspaper print, recognizing faces across a room). Potential scores range from 0 to 15, with higher scores indicating more difficulty. This is a widely used scale with well-established validity and reliability.¹⁹

To assess life goals, participants were asked to list their three most important current goals. The question was phrased as follows:

I would like you to think about the goals, plans, and areas of your life that are the most important to you. These could include things that you would like to happen, as well as things you would like to maintain or avoid. Thinking of the goals that are important to you at this time, which would you consider to be the three most important?

If participants answered this question with a listing of general life domains (e.g. family) rather than goals (e.g. continue to take care of my children), we further probed: 'How is that a goal?' or 'What about that is a goal?' or 'What do you aim for with that?'

For each of these goals, they were then asked to rate on a scale from 0 to 10 (higher rating

reflecting more interference) the degree to which their vision impairment interferes with each goal. The interference of each goal was followed by the question ‘How do you deal with this?’. Interviewers documented verbatim the content of the responses during the interview for later coding. Data on coping were not included in the analysis for the present paper as addressing this aspect would have exceeded the scope of one paper.

Analytic strategy

A coding system for the various reported life goals was developed using a qualitative analytical approach. Two of the authors (LP, KB) independently reviewed the responses of the first 20 participants to generate an initial set of descriptive codes based on common themes reflected in the reported goals. For each goal, the authors also judged whether or not the goals were related to having a vision problem. They then met to discuss, clarify and refine the suggested codes. After agreeing on an initial set of codes and clarifying their definitions, the responses of the next 10 participants were used to establish inter-rater agreement between two independent coders. Percentage agreement was used to assess inter-rater agreement during this initial phase of code development, and was derived by dividing the number of codes in agreement by the total number of codes for each narrative. The first inter-rater agreements derived in this way were at 80% and above, which is generally considered an acceptable agreement rate.²⁰

The authors then proceeded to gradually incorporate the whole sample in a careful process of coding a set of 20 participants at a time, meeting to discuss the coding and calculate inter-rater agreement, and then moving forward with another set of responses. For all coding stages following code development, the more conservative Cohen’s kappa (that takes into account agreement occurring by chance) was used to assess inter-rater agreements. These rounds of coding all produced kappa coefficients that consistently ranged from 0.91 to 0.95, with an average kappa of 0.93, demonstrating adequate inter-rater agreement using the coding system for life goals.

Next, descriptive analyses were used to identify the frequencies of important life goals identified by

the participants. We assessed the number of occurrences for each goal in two ways: First, we determined the number of participants reporting each goal at least once. Second, we calculated the total number of occurrences for each goal. We then derived the frequencies and percentages of vision-related goals based on these total goal counts. We also created composite variables to cluster the individual goals within three larger domains (functional, social, and psychological), and calculated frequencies and percentages for these domains as well. We then calculated means and standard deviations of the interference rating for each goal and domain. Finally, we conducted chi square tests to examine if there were any differences in the types of goals identified depending on onset of vision loss, either before or at midlife.

Results

Sample characteristics are displayed in Table 1. Out of the 211 participants who reported their race, 117 were white, 66 were African-American, nine were Asian or Pacific Islander, two were Native American or Alaskan Native and 17 were other races. In terms of ethnicity, 23 participants considered themselves Hispanic. Of the 214 participants who reported their employment status, 60 were employed. Out of the 121 participants who were unemployed, 75 were unemployed because of vision loss, and out of the 33 participants who were retired, 18 were retired because of vision loss.

The first three columns of Table 2 display the different types of goals that were identified along with sample quotes to illustrate the coded themes, as well as the frequencies and percentages of participants who reported the particular goals at least once. It is noted that the *N*-values for the latter column are based on the total number of participants (*N* = 215) who each endorsed at least one goal, and could have up to three possible goals. Since each participant could have reported more than one type of goal (e.g. a participant may have three functional goals – career, education and leisure), the sum of the *N*-values of specific goals comes out to be more than the *N* of the overarching category (e.g. functional) in this column.

Table 1 Descriptive information for sample characteristics ($N=216$)

Variable	Mean (<i>SD</i>)	Actual range	<i>N</i> (%)
Gender (female)			122 (56.5)
Age	55 (6.8)	40–64	
Race (white)			117 (54.2)
Employed			60 (27.5)
Onset of vision loss during midlife ^a			178 (81.7)
Functional Vision Loss Scale	12.02 (2.39)	0–15	

^aOnset of vision loss at or over the age of 40.

As predicted across the three domains, functional goals had the highest occurrence and were reported by the vast majority of participants. Social goals were reported by a third and psychological goals by a tenth of participants. Among functional goals, career, daily tasks, mobility, vision, health and independence goals were identified by the highest percentage of participants. Among the social goals, family goals were identified most frequently. Among the psychological goals, life quality was identified most often. In addition, people rarely identified goals from the same category more than once. A few exceptions were daily tasks, which were reported by 17 people; leisure, reported by 6 people; and career, reported by 5 people more than once.

The fourth and fifth columns of Table 2 depict frequencies and percentages for the occurrence of individual goals and the occurrence of individual goals that were coded as vision-related. The majority of the reported functional goals, and almost a third of the social goals appeared to be vision-related. Even though psychological goals were infrequently reported, almost half were vision-related. Among functional goals, the identified goals that were nearly always vision-related were daily tasks, mobility, and independence. Education and career goals were mostly vision-related, whereas this was only the case for half of the leisure goals, and infrequently the case for general health and financial goals.

In terms of combinations of reported goals, there was a tendency to have a mixture of vision- and not vision-related goals, as predicted. Across the three most important goals, the majority of participants ($N=168$) reported at least one vision-related goal (146 participants reported at least two vision-related goals).

Just over one-third of participants ($N=79$) had all vision-related goals and only about a tenth ($N=24$) had all not vision-related goals. Thus, a larger number of participants reported three goals that were vision-related, than those who reported three goals that were not vision-related.

The study's open-ended methodology revealed the content of the particular goals participants stated as being their most important, and it was the actual content of the goals, as opposed to the domain and code assigned to it, that revealed the nature behind the stated goals as being related to vision loss. For example, career goals are a common priority in midlife. However, the career goals reported by our participants indicated a difficulty in continuing to work because of vision impairment. The sample quote column in Table 2 includes examples of such vision-related goals (these sample quotes are marked with ^a). Overall, the functional domain involved more task-oriented vision-related goals, such as reading, walking outdoors, working and being independent. The vision-related goals from the social domain were related to maintaining relationships, and those from the psychological domain were associated with maintaining or enhancing life quality and coping with vision loss.

As predicted, with regard to interference levels (see column 6 in Table 2), we found that participants reported the highest interference in functional and social goals and the least interference in psychological goals. For most goals, the average interference scores were in the middle range (5–7); the only exceptions were health, spouse, spiritual and self-improvement goals, with rather low interference; goals with markedly high interference levels were daily tasks, mobility, independence and leisure.

Table 2 Goal themes with sample quotes, as well as frequencies, percentages and mean interference levels of reported goals

	Participants who reported goals ^b		Occurrence of goals ^c		Vision-related goals ^d		Goal interference	
	N	%	N	%	N	%	M	SD
Functional	214	99	506	82	371	73	6.02	1.0
Career	94	44	99	16	62	63	5.71	3.4
Daily tasks	71	33	90	15	87	97	7.22	2.6
Mobility	64	30	67	11	64	96	7.41	2.6
Vision	54	25	55	9	55	100	5.31	3.8
Health	44	20	45	7	5	11	4.43	3.1
Independence	43	20	43	7	43	100	6.15	3.0
Leisure	42	19	48	8	25	52	6.64	2.7
Educational	35	16	37	6	29	78	5.89	3.0
Financial security	22	10	22	4	1	0.05	5.40	3.2
Social	72	33	79	13	27	30	4.76	1.5
Family	42	19	46	7	15	33	5.37	3.5
General social	18	8	18	3	10	60	5.28	3.5
Spouse/partner	10	5	10	7	1	10	2.60	2.5
Community involvement	5	2	5	1	1	20	5.80	3.5
Psychological	28	13	28	6	13	46	3.96	1.8
Life quality	15	7	15	2	6	4	5.70	2.8
Adjustment to vision loss	7	3	7	1	7	100	5.40	3.6
Spiritual/religious	4	2	4	1	0	0	2.25	3.7
Self-improvement	2	1	2	0	0	0	2.50	3.5

^aSample quote for a goal that was also coded as being vision-related.

^bPercentages based on 215 participants who reported goals.

^cPercentages based on total reported goals N=619.

^dPercentages based on total number of goals in individual categories.

With regard to onset of vision loss, career ($N=125$ versus $N=86$, $\chi^2=3.88$, $P<0.05$), education ($N=62$ versus $N=30$, $\chi^2=5.52$, $P<0.05$) and financial goals ($N=39$ versus $N=17$, $\chi^2=3.42$, $P<0.10$) were more often reported by those who had their onset before midlife, whereas mobility ($N=69$ versus $N=39$, $\chi^2=2.78$, $P<0.10$) and independence ($N=49$ versus $N=11$, $\chi^2=6.20$, $P<0.05$) goals were more common among those who had their onset more recently, during midlife. Thus, goal identification was related to the timing of vision loss onset primarily for functional goals. With regard to the social and psychological domains, life goal identification did not differ between the two groups.

Discussion

This study investigated the implications of vision loss in midlife by identifying the life goals that are important to middle-aged adults and assessing how vision loss interferes with goal pursuit. Consistent with previous work on life goals among adults with vision impairment,¹⁴ functional and social goals were reported by the majority of participants and psychological goals were least reported. This is also in line with prior work on life goals and disability demonstrating great importance attached to functional and relationship-related goals in people with acute²¹ and chronic or progressive neurological disabilities.²² However, the present study exceeds this previous work by using open-ended assessments of personal goals rather than an a priori list of goals. This allowed us to gain more insight into the nature of goals reported by middle-aged adults with visual disability. Functional goals reported by participants included the abilities and tasks required to continue living independently and productively, including daily tasks, mobility, career and financial security. Social goals included taking care of family, and maintaining relationships with friends and significant others (see ref. 23 for study on relationship strategies). Psychological goals concentrated on preserving a positive life quality, adjusting to vision loss, achieving spiritual or religious endeavors and working on self-improvement.

This study showed that individuals with vision loss in midlife certainly endorse some of the same goals reported in the general midlife population.³

However, all three life goal categories contained goals that were specifically related to vision loss. These findings illustrate the extensive impact of vision loss on middle-aged adults. Most participants had a mixture of vision- and not vision-related goals; however, there were also participants in our sample who exclusively named vision-related goals. The fact that a mid-range level of goal interference was reported for a majority of the goals illustrates the degree to which vision loss interferes with achieving life goals. These findings emphasize that the goals of middle-aged adults with vision loss tend to be shaped by their visual disability.

Although the onset of vision loss did not play a role for life goal identification in the social and psychological domains, we found differences in the functional domain, suggesting that the time of onset is more likely to have an impact on goals that are instrumental in nature. Managing instrumental tasks are the primary challenges people have when experiencing visual disability. Interestingly, the goals that are more related to managing the tasks of everyday life (i.e. mobility and independence goals) were endorsed by those who had their onset during midlife; while the goals that seem more typical of middle adulthood (i.e. career, education and financial goals) were more likely to be endorsed by those who had the onset of vision loss prior to midlife. One possible explanation for these findings is that those who had a more recent vision loss had greater urgency to focus on more immediate, pragmatic daily tasks, whereas those with an earlier onset of vision loss had already found ways of managing these types of tasks and were thus in a better place to pursue some of the broader, more long-term life goals, such as career and education.

The narratives of the study's open-ended questionnaire allowed us to uncover the unique nature of the content of life goals held by middle-aged adults with vision impairment. Some of the goals seemed to more directly reflect the life situation of someone with a visual disability, such as daily tasks and mobility. Accomplishing everyday tasks such as these depends on basic abilities, such as reading, writing and getting around, all of which require vision. Other goals appeared to be more typical mid-life goals, such as working on one's career and improving aspects of family life. However, in these

cases, the content of the goal often reflected the adaptive challenges resulting from vision loss. Thus, our findings indicate that the goals that middle-aged adults with visual disabilities are struggling to accomplish are differentially impacted by this disability; some goals appear to be new and the direct result of functional limitations because of the vision loss (e.g. mobility), while other goals seem to reflect a reframing of existing goals that take into account challenges posed by vision loss (e.g. continue helping my children with their schoolwork despite limited visual ability). Thus, similar to prior studies,^{14,15} this study suggests that life goals are an important area of inquiry and clinical care given their unique and central role in the daily lives and well-being of individuals with visual disabilities.

Several limitations of the present study need to be acknowledged. The participants were drawn from middle-aged adults who have sought vision rehabilitation services; thus, this study has limited generalizability to visually impaired adults who do not seek out services, or to adults with other chronic impairments. Since the study used only one time point of measurement, we cannot draw conclusions about causality regarding the impact of visual disability on life goals of middle-aged adults with vision loss. We also cannot tease apart which goals were either already altered or in the process of being altered when we interviewed our participants. However, our findings did show that having onset of vision loss during rather than prior to midlife made the reporting of certain goals more likely, suggesting that some of the reported goals represented 'adapted' aspirations and priorities.

Clearly, our findings demonstrate that visual disability in middle adulthood is a great barrier to achieving the multitude of goals that individuals typically need to accomplish at this point in life. Given that midlife is typically characterized by the pursuit of an intricate web of goals that can be greatly complicated by such a disability, research and rehabilitation services are especially suited to assist middle-aged individuals coping with visual disability learn ways to effectively adapt their goal pursuit to optimize well-being. Our data show great diversity in the types and content of reported goals and significant levels of interference for many of them, underscoring the need for vision rehabilitation to carefully assess client's life goals and to tailor services to the particular needs of the clients in addressing these goals.

Previous work has shown that vision rehabilitation programmes do not typically assess client's life goals in a systematic way, and that rehabilitation often fails to successfully address difficulties that clients experience in their pursuit of important life goals.¹⁵ The findings from the present study lend further support to the previously expressed notion that vision rehabilitation programmes need to pay closer attention to social and psychological goals in addition to their more traditional focus on functional issues.^{14,15}

Moreover, as our data show that participants' goals were affected by their visual disability, not only with respect to interference with the goals but also in terms of the content of some of the goals, we suggest that rehabilitation planning should encompass both a systematic assessment of personal goals as well as a programme component regarding future steps managing and engaging with those goals. This programme component can assist clients with a careful analysis of their important goals in terms of feasibility, and offer guidance and counsel on how to work towards an accommodative rethinking or modification of unfeasible goals. For goals that have become challenging but remain feasible, this programme component can provide problem-solving support and planning in terms of how to continue goal pursuit. Thus, rehabilitation services can not only more effectively assess the life goals of individuals with visual disability, but also provide guidance and support to help these individuals adapt to their disability and continue to live meaningful, goal-driven lives.

Clinical messages

- Visual disability in middle adulthood can be a great barrier to achieving the multitude of goals that individuals typically need to accomplish at this point in life.
- Vision rehabilitation programmes should pay closer attention to social and psychological goals, in addition to their more traditional focus on functional issues.
- A systematic review of clients' life goals and the vision-related interference they experience in their goal pursuits may be a helpful step in the context of vision rehabilitation services.

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Competing interests

None.

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Contributors

LP (guarantor) was instrumental in all aspects of study implementation. She also collaborated with KB in coding the open-ended data on life goals, as well as the analysis of this data, and the interpretation of the findings. LP headed the writing effort for the manuscript with KB's and SW's assistance.

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