



# 耆趣藝遊——賽馬會健腦行計劃

JOURNEY FOR ACTIVE MINDS  
JOCKEY CLUB MUSEUM PROGRAMME FOR THE ELDERLY

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博物館參觀與活動為腦退化症患者與其家人  
改善生活質素的效能研究

*Effectiveness of museum visit and activities on enhancing the quality of life  
of people with dementia and their caregivers*

期末報告

FINAL REPORT

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香港中文大學

The Chinese University of Hong Kong

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## 引言

腦退化症是影響認知及執行能力的腦部退化障礙，對日常生活帶來負擔 (APA, 2013)。腦退化症分為不同類型，最普遍的阿爾茨海默症總共影響六至九成腦退化症患者。其他較為普遍的腦退化症類型包括影響二至三成患者、由慢性腦血管栓塞引起的腦退化症，並影響一成至一成五患者的利維體腦退化症。腦退化症的類型根據引發原因及症狀分類，例如阿爾茨海默症的特點是患者腦部出現原因不明的澱粉蛋白質斑與纏結，而慢性腦血管栓塞相關的腦退化症則因為流經腦部的血液減少而引致。患者有可能同時受多於一種腦退化症影響 (ALZ, 2015)。

身理機能及精神衰退往往成為關係的障礙。有研究指出腦退化症患者 (PWD) 的家人因著患者未能維持發病前的溝通能力，而感受到關係變質 (DeVugt et al., 2003)。而日常功能上的退化，亦另不少人逼於無奈地退出既有的社交和家庭活動，過去的研究亦有指出腦退化症患者的孤單及忽略感 (Phinney et al., 2007)。

一個人縱使在記憶及技能上出現退化，但仍有潛能參與各種有意義的活動，而博物館或許能夠為這些活動提供一個理想平台 (Parsa et al., 2010)。有指博物館的展品能夠連結個人經歷並觸動情感流露，因此可以刺激有意義的回應。亦有人指出導賞活動能夠提供即時而且富有彈性的回應，並且營造一個溫馨的參與氣氛。至於博物館則能夠為參觀者提供一個不受殘障所影響的社會身份：不論是照顧者還是被照顧的人，所有人的參與同等重要 (Silverman, 2002)。

紐約市的現代藝術博物館 (MoMA) 既是一個藝術機構，亦為腦退化症患者提供衛生服務。MoMA 是首間為輕度至中度腦退化症患者開設特別工作坊及藝術探索導賞服務的博物館，為患者及他們的家人提供「抒發渠道以及對話平台」(p.94) (Rosenberg, 2009)。

2013年，香港賽馬會慈善信託基金 (HKJCCT) 與康樂及文化事務署 (LCSD) 均認為 MoMA 的工作能為

腦退化症患者提供有效益的服務，並可考慮將類似計劃引進本港博物館。

香港的博物館能為長者及腦退化症患者提供懷舊回憶和分享藝術探索經驗的理想環境。懷舊回憶是透過懷緬舊事、舊物及過去的日子，促進患者的記憶。參觀體驗涵蓋觀賞、分享及討論有藝術及歷史特色的展品，如：生活舊相片、服裝飾物、傢具、圖案、圖畫及日常用具等，有助參觀者表達意見和對話 (Beshwate & Kasin, 2010)。另一方面，參與特別設計的工作坊，其中的藝術及文化探索讓腦退化症患者和他們的家屬照顧者在刺激記憶，分享經驗及互動交流中有所得益，建立患者的力量及平和感、信心及身份認同 (Rhoads, 2009)。

由康樂及文化事務署主辦、香港歷史博物館籌劃、藝術在醫院協辦，香港賽馬會慈善信託基金獨家贊助的「耆趣藝遊 —— 賽馬會健腦行」先導計劃，於二零一四年開始舉辦，是香港首個以長者及腦退化症患者為主要服務對象的博物館活動。透過特別導賞團、工作坊及外展活動，鼓勵參加者及其家屬一同分享回憶及互動交流，藉以刺激思維；並培養長者及腦退化症患者對香港歷史、藝術及文化遺產的興趣，拉近與社區的距離。

本研究由康文署委託進行，香港中文大學 (中文大學) 負責收集部分參與者的數據，並輸入資料、進行分析，以及撰寫報告，而「藝術在醫院」(AIH) 及香港歷史博物館 (HKMH) 則分別負責招募參觀者，與收集部分參與者的數據。本研究的目標為評估和探討本項目的影響及成效，以及香港歷史博物館安排的教育活動如何提升腦退化症患者、他們的家人，以及沒有患腦退化症的人士 (PWOD) 的生活質素。

## 方法

### 參加者

經確診患上腦退化症的六十歲或以上長者，通過香港的日間中心參與是此研究。除卻參與半日活動的行動能力以及基本溝通與回應訪問的能力以外，研究並沒有要求參加者符合其他任何參加條件。所有腦退化症患者的家屬都被邀請陪伴家人參與活動以及接受訪問，每名腦退化症患者與自己的一名家人組成一對「組合」，接受觀察研究。而沒有認知障礙、並年滿六十歲的長者，亦在活動之後就他們的導賞經歷接受訪問。

### 樣本數

研究目標為招募50對腦退化症患者及他們的家人，以及1000名沒有患上腦退化症的長者。在收集資料的過程中，共有46名腦退化症患者及653名沒有患上腦退化症的長者接受研究。

### 研究設計

AIH邀請日間中心使用者報名參加於歷史博物館對外關閉的日子(星期二)舉行的活動。每一次參觀由歷史博物館內的導賞團及相關主題的藝術工作坊組成。研究以心理健康評估工具調查參加者的情緒、生活質素及心理健康。資料以不同形式收集：由家屬自行填寫的問卷、由研究員詢問參加者所得的非開放式題目，以及由研究員完成的觀察研究調查表。研究通過比對參加者參與活動前後的評估分數，以及分析研究員的觀察，評估「耆趣藝遊——賽馬會健腦行計劃」的成效及可行性。同時，研究亦以微型小組討論與訪問的方式收集更深入的意見，而收集深入意見的形式則取決於參與者的配合能力。

### 評估工具

研究使用的評估工具與問卷臚列如下：

#### 1. 阿氏癡呆症生活質素量表(QoL-AD)

生活質素由阿氏癡呆症生活質素量表(QoL-AD)量度。QoL-AD由13個條目組成，特別為評估患腦退化症的人士而設計。分數愈高，代表自我評估的心理健康更好。

#### 2. 臉譜量表(SFAS)

情緒由臉譜量表(SFAS)量度。量表只有一個條目，受訪者被邀請從五個代表遞進心情的臉譜當中，選擇一個以表示自己當刻的心情(非常不開心、有點不開心、中立、幾開心、非常開心)。分數愈高，代表心情愈好。

#### 3. 通用健康問卷(GHQ-30)

心理徵狀以通用健康問卷調查。問卷由30個有關徵狀頻率的條目組成，例如「因為擔心而睡不著」、「心情煩躁以致睡得不好」，和「覺得整天有精神壓力」。分數愈高，代表心理健康愈差。

#### 4. 增潤問卷-A(問卷A)

問卷A調查參觀活動的一般觀感(11個條目)以及參與者的個人資料(3個條目)。增潤問卷由非開放式條目組成，並由沒有患上腦退化症的長者自行完成。

#### 5. 增潤問卷-B(問卷B)

問卷B調查參觀活動的一般觀感(8個條目)以及參與者的個人資料(2個條目)。增潤問卷由非開放式條目組成，並由腦退化症患者的家屬自行完成。

#### 6. 增潤問卷-C(問卷C)

問卷C調查參觀活動的一般觀感(11個條目)。

增潤問卷由非開放式條目組成，並由研究員協助腦退化症患者完成。

#### 7. 增潤問卷-D(問卷D)

問卷D調查腦退化症患者的個人資料(5個條目)。增潤問卷由非開放式條目組成，並由中文大學研究員以訪問形式協助腦退化症患者的家屬完成。

#### 8. 增潤問卷-E(問卷E)

問卷E調查參觀活動的一般觀感(19個條目)以及參與者的個人資料(6個條目)。增潤問卷由開放及非開放式條目組成，並由腦退化症患者的家屬自行完成。

#### 9. 觀察調查

研究員於導賞活動及工作坊期間進行觀察，以調查腦退化症患者與導賞員、家屬並其他長者的互動。

### 資料收集與分析

問卷

1. 給予沒有患上腦退化症的參觀者的問卷(PWOD) 沒有患上腦退化症的參觀者各自於導賞活動開始前、並工作坊完成後，獲發自行填寫的SFAS，以及問卷A。整份問卷由沒有患上腦退化症的長者自行完成，而HKMH則負責送遞、收集，並檢查問卷。

#### 2. 給予腦退化症患者的簡版問卷(PWD-SV)

不願意參與深入研究的腦退化症患者獲發一份簡版問卷。問卷由自行填寫的SFAS組成，並於導賞活動開始前、並工作坊完成後填寫。如果參加者有家屬陪同，家屬會獲發自行填寫的問卷B。HKMH負責送遞、收集並檢查問卷。

#### 3. 給予腦退化症患者的完整版問卷(PWD-FV)

願意參與深入研究的腦退化症患者並他們的家人會獲發PWD-FV。

腦退化症患者一共接受四次訪問。QoL-AD和SFAS在第一次參觀博物館前進行；SFAS在完成第一次博物館參觀的工作坊活動後進行。如果腦退化症患者第二次參觀博物館，SFAS在第二次參觀博物館前進行。QoL-AD、SFAS和問卷C於第二次博物館參觀活動後，或完成第一次博物館參觀後的兩個月以內進行。所有訪問由中文大學研究員負責。

陪同腦退化症患者的家屬照顧者與第一次參觀以前獲發GHQ-30。於第二次參觀後，或完成第一次博物館參觀後的兩個月以內，家屬會獲發以自行填寫模式完成的問卷E，和經研究員訪問完成的問卷D。所有訪問由中文大學研究員負責。

### 程序

資料收集由2014年11月至2015年5月。AIH通過香港的日間中心招募參加者。研究對象的同意書由AIH於參觀之前，或訪問開始之前收集。腦退化症患者於每次參觀前後都會由一名研究員訪問以收集資料。在每一次參觀中，一名研究員會負責觀察患者與家人的溝通模式，並完成觀察問卷。PWD-SV和PWOD兩份問卷由HKMH負責送遞，並由參加者在HKMH職員協助下自行完成。

### 分析

數據分析以統計軟件SPSS(第22版)進行。數據經整理後，以頻率、平均值及標準差(SD)形式報告。顯著性差異分析以t檢驗方式進行。

## 結果

### 參與者個人資料

各項問卷的完成人數臚列如下：

- PWD-FV:** 33名腦退化症患者完成PWD-FV的前後測，25名家屬完成PWD-FV的前後測；
- PWD-2V:** 13名腦退化症患者完成PWD-FV的前後測，12名家屬完成PWD-SV的前後測；

- PWOD:** 653名沒有患上腦退化症的長者完成問卷。

於本報告中，由於資料缺失(i.e.有參與者未有完成部分條目)，研究人數與獨立條目的報告人數可能有出入。

表格1 顯示參與研究的參加者的背景資料。

表格1 參加者的背景資料

	PWOD (N=653) N (%)	PWD-SV (N=13) N (%)	PWD-FV (N=33) N (%)	CG (N=25) N (%)
<b>性別</b>				
男	167 (25.8%)	5 (38.5%)	13 (39.4%)	6 (24%)
女	481 (74.2%)	8 (61.5%)	20 (60.6%)	19 (76%)
<b>年紀</b>				
49歲以下	-	-	-	3 (15.8%)
49-59	-	-	-	7 (36.8%)
60-69	189 (29.6%)	0	3 (9.4%)	4 (21.1%)
70-79	256 (40.1%)	3 (23.1%)	5 (15.6%)	0
80歲或以上	194 (30.4%)	10 (76.9%)	24 (75.0%)	5 (26.3%)
<b>教育程度</b>				
從未接受教育	147 (22.6%)	-	4 (12.1%)	
非正規教育	31 (4.8%)	-	4 (12.1%)	
小學	285 (43.8%)	-	16 (48.5%)	
中學	156 (24.0%)	-	7 (21.2%)	
大專/大學或以上	31 (4.8%)	-	2 (6.1%)	
<b>婚姻狀況</b>				
未婚	-	-	-	6 (24%)
已婚	-	-	14 (42.4%)	18 (72%)
鰥/寡	-	-	19 (57.6%)	1 (4%)
<b>腦退化症程度 (由照顧者評定)</b>				
初期	-	-	15 (46.9%)	-
中期	-	-	17 (53.1%)	-
<b>與腦退化症長者的關係</b>				
夫婦	-	-	-	8 (32%)
子女/媳婦/女婿	-	-	-	16 (64%)
其他	-	-	-	1 (4%)
<b>過往的博物館活動經驗</b>				
有參加過展覽和活動	489 (75.3%)	-	17 (53.1%)	20 (80%)
沒有參加過展覽和活動	160 (24.7%)	-	15 (46.9%)	5 (20%)

注: PWOD=沒有患上腦退化症的長者; PWD-SV=腦退化症患者(簡版); PWD-FV=腦退化症患者(完整版); CG=腦退化症患者的家屬照顧者; 百分比與數目的差異由資料缺失導致。

### 長者的情緒健康

表格2及3顯示參加者的評估分數。

- 沒有患上腦退化症的長者 (N=639)**

沒有患上腦退化症的長者自行匯報的SFAS分數有顯著的提升。參加者在參觀博物館之前的情緒分數在5分中平均為4.44±.026分，分數在參觀後有上升，平均分為4.72±.021。情緒的改善達到數據學上顯著的差異(p=.000)。

- 腦退化症患者 (N=46)**

填寫簡版問卷的腦退化症患者(n=13)和填寫完整版問卷的腦退化症患者(n=33)都有匯報SFAS分數，而他們的數據經合併分析。參加者

在參觀博物館之前的情緒分數在5分中平均為4.00±.730分，分數在參觀後有上升，平均分為4.33±.732。情緒的改善達到數據學上顯著的差異(p<.05)。

- 腦退化症患者 (N=13)**

十三名腦退化症患者參觀了兩次博物館。參加者在第二次的活動中有情緒改善的趨勢。參加者在參觀博物館之前的情緒分數在5分中平均為4.00±.913分，分數在參觀後有上升，平均分為4.15±.689。比對兩次參觀的情緒上升，顯示第二次參觀時情緒改善幅度較小，但跌幅並未達到數據學上顯著的差異。

表格2 自行匯報的情緒 (第一次參觀)

	PWOD (N=639) M(SD)	PWD (N=46) M(SD)	PWD-FV (N=33) M(SD)
參加前	4.44 (.03)	4.00 (.73)	3.85 (.76)
參加後	4.72 (.02)	4.33 (.73)	4.21 (.78)

注: PWOD=沒有患上腦退化症的長者; PWD-SV=腦退化症患者(簡版); PWD-FV=腦退化症患者(完整版)。

表格3 自行匯報的情緒 (第二次參觀)

	PWOD (N=639) M(SD)	PWD (N=46) M(SD)	PWD-FV (N=13) M(SD)
參加前	-	-	4.00 (.91)
參加後	-	-	4.15 (.69)

注: PWOD=沒有患上腦退化症的長者; PWD-SV=腦退化症患者(簡版); PWD-FV=腦退化症患者(完整版)。

### 生活質素

腦退化症患者在第一次匯報的生活質素(N=33)在52分中平均為32.06 ± 5.87。他們在

其後的匯報中平均分為35.15 ± 6.62。比對兩次結果，顯示參加者的生活質素有顯著上升，升幅達到數據學上的顯著差異。

表格4 腦退化症患者自行匯報的生活質素(N=33)

	M(SD)
參加前	32.06 (5.87)
參加後	35.15 (6.62)

## 7. 腦退化症患者的家屬

在第一次參觀前(N=25)自行匯報的心理健康平均分為32.84 ± 8.34。在參觀後(N=25)自行匯報的心理健康平均分為35.36 ± 7.02。比對兩次結果，顯示家屬的心理健康有退步，但跌幅並未達

數據學上的顯著差異。因子分析顯示家屬在「焦慮」和「睡眠失調」兩方面有數據學上顯著的改善，而在「不適當應對」和「人際關係失調」兩方面有數據學上顯著的退步。

表格5 腦退化症患者家屬自行匯報並評估的心理健康(N=25)

	參加前 M(SD)	參加後 M(SD)	顯著度
總分	32.84 (8.35)	35.36 (7.02)	n.s.
焦慮	6.28 (3.94)	5.92 (3.59)	.000
抑鬱	2.40 (1.35)	3.16 (1.95)	n.s.
不適當應對	11.56 (2.20)	14.40 (2.08)	.012
人際關係失調	9.48 (2.57)	10.80 (1.32)	.014
睡眠失調	1.28 (1.37)	1.08 (1.35)	.010

注: PWOD=沒有患上腦退化症的長者; PWD-SV=腦退化症患者(簡版); PWD-FV=腦退化症患者(完整版)。

### 導賞活動與藝術工作坊進行期間的溝通和參與

14對參加者於第一次參觀時接受觀察研究，7對參加者於第二次參觀時接受觀察研究。由於只有5對參加者於兩次參觀時都有接受觀察研究，本報告並未有羅列該5對參加者於兩次參加時的分別。

表6顯示腦退化症患者在兩次參與導賞活動過程的溝

通規律。參觀第二次的人士與導賞員和其他長者有較少溝通，他們對家人作出較少肢體溝通，而且顯示較少正面情感。然而，他們與家人的語言溝通則有上升。有關腦退化症患者與家人之間的溝通改善於定性研究部分有更詳盡的探索。

表格6 腦退化症患者於導賞活動期間的參與規律

	第一次參觀 (N=14) (M)	第二次參觀 (N=7) (M)
與導賞員之間的語言溝通	41.21	19.29
與其他年長參觀人士之間的語言溝通	4.50	1.57
與家人之間口述溝通	41.36	58.71
與家人之間的肢體溝通	14.07	11.86
正面情緒	23.93	11.43
負面情緒	0.93	0.57

注：參與規律以觀察對象作出的語言或非語言溝通行為，或展示的正面或負面情緒次數作為量度。

表7顯示腦退化症患者在兩次參與藝術工作坊的溝通規律。參觀第二次的人士在工作坊中與藝術家的溝通稍微減少，但亦稍微更積極地和其他長者溝通。

與導賞活動的規律相近，他們與家人的語言溝通有增加。而從觀察所得，參加者在兩次工作坊中顯示的正面情緒相近。

表格7 腦退化症患者於導賞活動期間的參與規律

	第一次參觀 (N=14) (M)	第二次參觀 (N=7) (M)
與藝術家之間的語言溝通	10.93	9.43
與其他年長參觀人士之間的語言溝通	1.00	2.29
與家人之間口述溝通	28.93	35.86
與家人之間的肢體溝通	9.79	4.14
正面情緒	12.50	12.71
負面情緒	0.57	0.29

注：參與規律以觀察對象作出的語言或非語言溝通行為，或展示的正面或負面情緒次數作為量度。

### 對參觀博物館的整體觀感

#### 1. 沒有患上腦退化症的長者(N=652)

表8顯示沒有患上腦退化症的長者對活動的評價。

受訪者對活動甚為正面。絕大部分認為自己很有可能在未來再度參與博物館活動，但較少人對手工藝相關的活動有興趣。

表格8 沒有患上腦退化症的長者對活動的評價 (N=652)

	%
參觀的內容有趣。	99.4
導賞員的講解清楚。	98.6
導賞員健談。	98.8
喜歡和其他長者一起參觀。	99.7
歷史博物館的環境舒服。	99.7
喜歡參觀後的工作坊。	98.5
會向親戚朋友分享今次的經驗。	98.5
有興趣再參觀歷史博物館的展覽。	98.2
有興趣以後自己做手工/ 勞作/ 畫畫。	84.4
整體而言對今次的參觀滿意。	99.7

#### 2. 腦退化症患者(N=33)

表9顯示腦退化症患者對活動作出的評價。患有腦退化症的參加者一般而言對活動感到滿意，但相比沒有患腦退化症的人士，他們對未來再度參觀和參與工作坊的動力較低。定性研究對這個部

分有較詳細的調查。然而，從觀察所得，有些參與者因著忘記部分參觀細節，而在訪問期間無法對某些項目做出評價(例：3名受訪者忘記導賞員，因此未能評價他/她的表達方式)。

表格9 腦退化症患者對活動的評價(N=33)

	%
參觀的內容有趣。	80.6
導賞員的講解清楚。	96.7
導賞員健談。	96.3
喜歡和其他長者一起參觀。	96.8
歷史博物館的環境舒服。	93.3
喜歡參觀後的工作坊。	83.3
會向親戚朋友分享今次的經驗。	76.7
有興趣再參觀歷史博物館的展覽。	78.8
有興趣以後自己做手工/ 勞作/ 畫畫。	75.8
整體而言對今次的參觀滿意。	96.7

### 3. 填寫簡版問卷的腦退化症患者家屬 (N=12)

填寫簡版問卷的腦退化症患者家屬對活動的評價羅列於表10。受訪者對活動的整體甚高。有些人指

出博物館的環境可以有改進空間。環境中令人感覺未如理想的部分，於定性研究有更詳盡的討論。

表格10 腦退化症患者家屬對活動的評價(簡版) (N=12)

	%
我照顧的長者享受今次的博物館參觀。	100
我照顧的長者享受今次的工作坊。	100
今次的活動促進我和我照顧的長者的溝通及交流。	100
今次的活動促進我照顧的長者和其他人的溝通及交流。	91.7
歷史博物館的環境舒服。	83.3
我有興趣再與你照顧的長者參觀類似的展覽。	100
整體而言對今次的參觀滿意。	100

### 4. 填寫完整版問卷的腦退化症患者家屬 (N=25)

表11顯示填寫完整版問卷的腦退化症患者家屬作出的評價。絕大部分患者的家屬為了讓長者有外出活動的機會而參與活動(92%)。稍微過半數照顧者為了和照顧的長者一起參加活動而被參觀活動所吸引(56%)。這兩項與定性研究的結果吻合，照顧者表示他們認為博物館活動是對腦退化

症患者的正面刺激，而且他們很珍惜與家人共渡的相處時間。

受訪者的滿意度在10分內由5至10分不等，而平均分為8.4分。絕大部分照顧者享受活動(95.8%)，並且認為他們照顧的長者享受活動(95.8%)。照顧者欣賞的部分以及對未來參觀的期望在定性研究中有更多討論。

表格11 腦退化症患者照顧者對活動的評價(完整版) (N=25)

	N (%)
參與活動的原因:	
想長者有外出活動的機會。	23(92%)
想和我照顧的長者一起參加活動。	14(56%)
自己喜歡博物館展覽。	6(24%)
最喜歡的活動部份:	
導賞員與長者的互動。	8(32%)
導賞員的講解。	7(28%)
工作坊。	7(28%)
沒有喜歡的部份。	3(12%)
最不喜歡的活動部份:	
參觀展覽安排。	3(12%)
工作坊安排。	1(4%)
導賞員的講解。	1(4%)
導賞員與長者的互動。	1(4%)
沒有不喜歡的部份。	19(76%)
我享受今次的活動。	23(95.8%)
我認為我照顧的長者享受今次的活動。	23(95.8%)
參觀的內容有趣。	24(96%)
導賞員的講解清楚。	25(100%)
我喜歡和我照顧的長者一起參觀。	24(96%)
我喜歡和其他照顧者一起參觀。	24(96%)
我認為今次參觀對我的好處:	
對我照顧的長者的看法/感覺更正面。	14(56%)
對我照顧的長者了解更多。	14(56%)
對我照顧的長者的能力有更正面的評價。	13(52%)
有機會和其他照顧者溝通。	12(48%)
我認為今次參觀對我照顧的長者的好處:	
長者參加活動後更開心。	22(88%)
長者有機會和其他人溝通。	17(68%)
長者參加活動後更有自信。	12(48%)
歷史博物館的環境舒服。	25(100%)
歷史博物館的環境適合腦退化症長者參觀。	24(100%)
參觀完後，我的心情變得更好。	16(64%)
我會向我的親戚朋友分享今次的經驗。	21(84%)
我有興趣再與我照顧的長者參觀歷史博物館的展覽。	23(95.8%)
我會考慮日後和我照顧的長者參與其他參觀或活動。	24(95.8%)
我考慮參與的參觀或活動:	
藝術工作坊。	20(80%)
其他博物館的展覽。	18(72%)
歷史博物館的其他活動。	17(68%)
歷史博物館的展覽。	12(48%)

注：百分比與數目的差異由資料缺失導致。

## 定性研究

15名照顧者與5名腦退化症患者參與了定性研究。研究包括共有5對患者並其家屬參與的兩個微型小組討論，以及個別訪談。參加者的年齡有47歲至87歲不等，男性佔6名，女性佔14名。

### 1. 經驗

照顧者與腦退化症患者普遍而言對博物館的經驗表示正面。不少人表示自己的情緒在參與活動之後變得更好，呼應定量研究的結果。

#### a. 導賞活動

絕大部分家屬與腦退化症患者都享受參與導賞活動，並且對與個人經歷相關的展品有最深刻的印象。大部分家屬與腦退化症患者認為導賞員的講解生動而清晰，亦與問卷的調查吻合。導賞員鼓勵參與者投入討論的方式為人讚賞：

「講解員很專業，會用各種方法去鼓勵他們，我參觀的時候覺得當時的互動以及老人家的反應不錯……他(導賞員)講解典故時會特意引起他們的興趣，例如在士多提及從前的馬標，因為他的刺激，參觀者人都很主動，會講起『我以前如此這般』，然後導賞員又會說『啊原來你咁叻架』，我覺得氣氛做得挺好。」(女兒, 57)

有些照顧者留意到他們的家人未能夠長時間專注在導賞員的講解，很有可能因為某些人受腦退化症影響而專注力減弱。有些照顧者提議導賞員可以更留意腦退化症患者的需要，並且在語速、語調和強調重點等方面作出調整。少數照顧者亦認為在大熒幕上播放的紀錄片或者能夠吸引那些沒有興趣聆聽講解的人。

#### b. 工作坊

絕大部分照顧者欣賞工作坊。有照顧者指出工作

坊能夠鼓勵那些在導賞環節較為被動的人投入參與，因為工作坊給予他們一件特定的任務。照顧者珍視與家人一同合作完成作品，並認為那是展示關愛的機會。有些照顧者指出他們的家人在家中甚少進行手工藝，但因著有家人陪同，他們就很樂意參與。少數照顧者指出他們在家裡有展示作品，一名照顧者特別指出他從配偶身上觀察到的成就感：

「我們做了一件非常美麗的東西，一件好漂亮的……現在掛在客廳，當有人客來坐的時候他們看見都說漂亮。[我太太]和其他人說是她做的……她當然開心，她覺得自己好叻好光榮。」(丈夫, 85)

照顧者對藝術品有不同評價。畫作以及簡單的手工藝，例如水壺模型，都很受歡迎，而家屬亦認為逐步的指示足夠清晰，並且容易跟隨。與之相反，其中一件作品(紙臉譜)則被指涉及抽象概念及複雜的技巧，因此照顧者認為作品不太適合。

#### c. 活動環節

大部分家屬覺得導賞團的長度及工作坊不應該再增長，因為時間增長的話，他們的家人或者會感覺疲憊。有些傾向希望延長節目內容的家屬指出他們的家人會需要充裕的休息時間，以維持足夠精力。

絕大部分家屬表示他們希望在現有的時間中安排更豐富的節目。他們認為簡單的小食能夠刺激腦退化症患者的快樂情緒，並且鼓勵他們更加投入。數名照顧者亦指出導賞活動只涵蓋了一個樓層的展覽，並表達希望能夠在導賞活動中多看一些內容。其他建議的增潤環節包括小休環節，以給予照顧者有溝通機會，還有安排予腦退化症患者的簡單運動項目。

#### d. 特別安排

大部分的照顧者覺得在博物館對外閉館的時段參觀，能夠「令環境更為安靜」、「避免參觀人士走失」、「騰出更多空間」，並「容易管理」。有人指出年長參觀者步行速度較慢，如果展館太擠擁，會造成不便。數名照顧者以指出參觀組別是「特別人士」，有人因此提出安排可能會強化分化的概念，但同時承認家人好像並未在意。一般而言，照顧者普遍認為這個安排能夠鼓勵更好的參與：

「這樣幫助爸爸更專注，他不會東張西望。老人家的聽力不好，如果環境的噪音太大，他們會很難聽得清楚。」(女兒, 53)

大部份照顧者滿意旅遊巴接送安排。有參加者指出旅遊巴減低交通上的不便及避免親人在戶外受熱，可以令到親人有一個好心情開展活動。對行動不便的人士而言，這個安排令行程更為便利；對其他人而言，點對點服務令他們心理上可以更放鬆：

「(如沒有旅遊巴)我不會參觀博物館，我怕他(丈夫)會走失。我外出時不會用複雜的交通……我很少去九龍，有了旅遊巴就方便多了。」(妻子, 52)

有些人認為到達時的經驗有點混亂。一名駕駛到博物館的照顧者表示指示不清晰，那家庭沒留意集合地點，他們走到正門，然後發現門已關上。

#### e. 環境

和定量研究結果相同，照顧者一般認為博物館很舒服，亦認為博物館空曠及有足夠的殘疾設施。但是，一半照顧者對燈光表示關注。在昏暗的環境中，參加者較易感到睡意，集中力亦較差。照顧者亦指出在有地氈的範圍，需要較強的燈光以防止長者跌倒：

「我想最大的問題是他的眼睛不好，他看展品有困難……我想這對有腦退化症人士而言是普遍的，他們不喜歡黑暗的地方，(在這些地方)他們開始蹣跚。」(女兒, 50)

#### f. 步速及步量

幾位照顧者認為參觀時間頗緊迫，參觀隊伍一般頗長，行動較慢的參加者未必能聽得清楚導賞員的講解，在前面的參加者則要等待後面的參加者。座位安排是必須的，所有參與小組討論的人士均說他們在參觀過程中不感到疲倦，這與照顧者的觀察結果相同。

## 2. 滿意度

### a. 社交及有意義的時光

大部份參加者對本項目有正面評價。他們認為本項目是一個與家人分享寶貴時光及顯示他們的愛的機會。一名有腦退化症的妻子因為她的伴侶能參加本項目而感到高興：

「帶他到處看，我看時，他也可以看。」(腦退化症人士, 女性, 87)

有些照顧者因為在參觀及工作坊期間盡力照顧家人而沒有太多機會與其他照顧者交談，但在走動期間則有些交談。一名配偶照顧者形容他們的交談：

「和其他長者，有時我們會交換我們的看法，這蠻好的。『你帶你的家人來，覺得如何呀?』『你日常的照顧是怎樣的呀?』(我可以)感受及聆聽，及和其他提供照顧的人交談。」(丈夫, 87)

### b. 懷緬促進溝通

與個人經驗有關的展品，例如涼茶舖及舊式士多，最為參加者記得。在小組討論中，參加者述

說他們過往的經歷，這些對話也在博物館裡發生。大部份照顧者喜歡展覽主題，他們認為展品引起長者情緒上的共鳴，很多照顧者都因為親人能就著展品講述自己的故事，以及和他們分享他們以前不知道的資訊，例如童年經歷，而感到高興。一名妻子特別指出他的丈夫在博物館的改善：

「他很少說話，除非我跟他說話，通常我都是問他今天其麼日子或月份……(在博物館內)他一路走一路說話，和我談起工展會、小時剪頭髮，及其他舊事例如涼茶舖。」(妻子, 66)

### c. 持續性

所有照顧者均同意本項目對他們的家人而言是一個享受的活動，亦指出「過程是最重要的」。有些照顧者指出他們的家人在參觀後，在家裡的情緒也較好，有些甚至指出在數天後，長者仍和他們談及參觀：

「沒有見到特別的東西，或沒有外間的刺激時，我們有時在家會沒有對話，但在參觀後，

有三、四天我們有新話題，爸爸會談及以前的米舖及涼茶舖。」(女兒, 53)

### 3. 動力

除了一名照顧者，其餘照顧者都表示他們有興趣參觀其他博物館。三分一照顧者提到他們不會與家人再參觀歷史博物館，因為已沒有新鮮感。一名照顧者觀察到她的母親在第二次參觀時沒太大興趣。

有些照顧者說家人只要「有外出活動」就很高興，這「比留到家要好」，有些則認為本項目本身能刺激長者活動，內容不太重要。一名配偶照顧者說：

「我想，懷緬是好的。他提及臨屋，制水時四日一次供水的情況……我覺得他的腦內仍有記憶……他不太介意做了甚麼；他在兩次參觀的反應都差不多。」(妻子, 83)

一名照顧者講及她對本項目的理解：

「對我而言，看著他（父親）和其他人溝通，令我知道他情況也不是太壞，我珍惜和他共處的日子，有機會看到他。」(女兒, 57)

## 討論

具正常認知能力的長者及有腦退化症的長者的情緒在參觀及工作坊後均有顯著的改善。參加了兩次參觀的長者，雖然在個別參觀後的情緒均有改善，但兩次參觀的情緒改善差距則有輕微的下調，但本研究因樣本數不足，未能從而得出具結論性的分析，但研究結果顯示，一次參觀可能已足以改善參加者的情緒。

有腦退化症的長者的自我感覺的生活質素在參觀後有顯著改善，定性研究結果顯示這可能與能外出活動、因展覽而懷緬過往時光、及做手工有關。

家屬照顧的自我感覺生活質素則在兩次參觀後差了，其中在「不適當應對」及「人際關係失調」兩個選項有顯著下調。本次項目沒有包含適對的訓練，所以照顧者未必會從本項目得到相關協助，在「不適當應對」這選項沒有改善顯示他們可能需要其他介入。

在定性研究，有些照顧者表示他們在參觀及工作坊過程中很盡力照顧家人，以至沒有足夠時間和其他照顧者交談，他們盡力照顧長者而沒有和其他人交談可能解釋了在「人際關係失調」選項中沒有改善。另一方面，他們在「焦慮」及「睡眠失調」這兩個選項有顯著進步，這顯示本項目能做到改善參與者的心理質素，從而可以減輕照顧者的焦慮，然後這可以促進照顧者有更優質的睡眠。

本項目中的參觀及工作坊被證明能幫助有腦退化

症人士及他們的家屬照顧者的溝通，包括傾談過事，或是一起完成手工藝等。照顧者均很重視他們的有腦退化症的親人的生活質素，希望他們能在家以外的地方亦能享受快樂的時光。另外，工作坊裡的手工製作為幾位參與的長者帶來成就感，成就感通常是長者患腦退化症後缺乏的，而這活動令長者重拾成就感，對他們的生活質素亦有裨益。這可以是一個有推動照顧者參與日後活動的有效的動力，尤其是那些平日受日間中心照顧的長者，因為他們一般都較少時間與他們的家屬照顧者有消閒活動。

本項目的成功亦歸功於是次主題，令到長者有機會懷緬過去，亦令照顧者可以更了解長者過往的生活。導賞員及工作坊導師的生動表述，特別是引用過往生活的例子，亦令整個體驗更正面。更慢的語速以及更誇張的語調會進一步吸引因患上腦退化症而集中力未能持久的長者。

安全感是照顧者很重視的一項，是次，博物館是在對公眾閉館的日子開放予有腦退化症的長者參加本項目，而交通亦以點對點形式安排，這都給予家屬照顧者一定程度的安全感。另一方面，博物館裡昏暗的燈光則令照顧者沒有安全感，他們擔心長者會因昏暗的燈光跌倒。

## 限制

本項目得到令人鼓舞的正面結果，但本研究的樣本數不多，令我們未能將本研究結果引申至整個腦退

化症人士族群。本研究沒有對照組，這令其他可能影響研究結果的因素未能得以測試。

## 結論及建議

本項目獲得參加者的高滿意度，這顯示本項目確能有效改善有腦退化症人士的心理健康，並令他們能有良好的戶外活動的體驗，在其中，他們能懷緬過往生活及製作手工藝，本項目亦提供機會予有腦退化症人士和他們的家屬照顧者溝通。

本研究結果支持一次參觀足以改善有腦退化症人士的心理健康。兩次參觀可能可以增進有腦退化症人士及他們的照顧者的語言溝通，但研究結果沒有進一步肯定兩次參觀在其他範疇的成效。事實上，香港人生活繁忙，照顧者或許難以抽空和親人作需要參觀兩次的活動。

其他對本項目的建議包括維持在對公眾閉館的情

況下安排本項目。照顧者明確指出這環境令他們更安心帶他們的通常較為體弱的親人出席活動。點對點交通安排亦有其需要，尤其是有腦退化症的長者在行動或乘搭交通方面可能遇到困難。另外，提供餐點可以進一步鼓勵長者參與。

完成手工藝令參加者有成就感，所以建議保留工作坊，而對有腦退化症人士而言，有一步一步的指示及不涉及抽象理念的手工製作會更受歡迎。日後的研究可以包括更大的樣本數及加入對照組，這樣可以提供更有力的實證以及幫助為有腦退化症人士設計最合適的欣賞藝術的活動。

## INTRODUCTION

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Dementia is a neurodegenerative disorder that influences an individual's cognitive and executive functioning to an extent that affects daily living (APA, 2013). There are several types of dementia, the most prominent type is Alzheimer's Disease, which accounts for 60 to 80 percent of dementia cases. Other types include vascular dementia, which accounts for around 20 to 30 percent of the cases; and dementia with Lewy bodies, which accounts for 10 to 25 percent of the cases, to name a few. Different types of dementia are categorized by the causes and symptoms, for instance, Alzheimer's Disease is characteristic of the abnormal presence of amyloid plaques and tangles in brain, while vascular dementia is caused by reduced blood flow to the brain. Sometimes a person may have more than one type of dementia at the same time (ALZ, 2015).

Decline in physical and mental capability intervenes as relationship obstacles. It is reported that family members of people with dementia (PWD) experience decline in relationship quality when a loved one failed to maintain pre-morbid communication (De Vugt et al., 2003). The weakening in functional abilities has contributed also to an involuntary withdrawal from social contacts

and family activities, and studies have reported loneliness and sense of abandonment among PWD (Phinney, Chaudhury, & O'connor, 2007).

Although people might experience severe deterioration in memory and skill, the potential to engage in meaningful experience remains, and museums might come to be an ideal platform for such experience (Parsa, Humble, & Gerber, 2010). It is argued that museum artifacts connected to personal experiences and triggered emotions, thereby stimulated meaningful responses. Guided tours were valued to be an instant, flexible, and warm engagement. And the museum as a whole has been suggested to empower visitors with social roles independent from any disability: be it caregiver or care recipient, all become equally important contributors during a visit (Silverman, 2002).

Bringing together dementia healthcare services and art institutions, the Museum of Modern Art (MoMA) in New York City was first to arrange specialized museum workshops and art exploration tours for people with mild to moderate dementia, opening up an "expressive outlet and a forum for dialogue" (p. 94) for both PWD and their caregivers (Rosenberg, 2009).

In 2013, the Hong Kong Jockey Club Charities

Trust (HKJCCT) and the Leisure and Cultural Services Department (LCSD) considered the MoMA's work was effective to dementia and the feasibility of developing such workshops in Hong Kong's museums.

In Hong Kong, Museum setting has an ideal ambience for both reminiscence and art-exploring experience, which could benefit the elderly and PWD in particular. Reminiscence refers to recollections of memories from the past. It is familiar to all of us and can be utilized for the benefit of others. Visiting experience involves viewing of and discussing art and history objects and elements like photographs, costumes, utensils, patterns and motifs, paintings, daily utensils etc. can serve as a useful tool to encourage self-expression and dialogue (Beshwate & Kasin, 2010). On the other hand, exploration on the arts and culture through specially designed workshops can benefit greatly PWD and their caregivers through intellectual stimulation, experience sharing and social interaction, giving PWD a sense of power, confidence, and identity (Rhoads, 2009).

Presented by the LCSD, "Journey for Active Minds: Jockey Club Museum Programme for the Elderly" is a pilot project organized by

the Hong Kong Museum of History (HKMH) in collaboration with the Art in Hospital (AIH) and is solely sponsored by the HKJCCT. The project, commenced in March 2014, is specially designed for the elderly and PWD, aiming to help them recall their memories, share experience, interact with others, foster interest in history, art and cultural heritage of Hong Kong and be stimulated intellectually through an array of museum programmes such as special guided tours, art and craft workshops and outreach activities. This project is the first museum programme specially designed for PWD ever held in Hong Kong.

This research was commissioned by LCSD. The Chinese University of Hong Kong (CUHK) was responsible for conducting the data collection of partial participants, data entry, analysis and research reporting, while AIH and HKMH were responsible for participant recruitment and data collection of partial participants respectively. The study aimed to evaluate the impact and effectiveness of this project and how the education activities organized by museum have helped to enhance the quality of life for PWD and the family caregivers of PWD, as well as people without dementia (PWOD).

# METHOD

## *Participants*

Elderly aged 60 years or above who were clinically diagnosed with dementia (PWD) were recruited through day care centers in Hong Kong. There were no exclusion criteria in recruitment except that participants were physically capable to manage a half day's activities and articulate to be interviewed. Family caregivers of PWD were encouraged to accompany their family members to the visit and participated in caregiver interview, each PWD was paired up with one of his/her caregiver, the two forming a "dyad" for research observation. Elderly (aged 60 years or above) with no cognitive impairment (people without dementia, PWOD) were also interviewed about their experience onto the tour.

## *Sample size*

It was targeted to recruit 50 dyads of PWD plus their family caregivers. It was also targeted to collect 1,000 valid questionnaires from PWOD. During the data collection, 46 PWD, 37 caregivers, and 653 PWOD valid samples were recruited.

## *Design*

Elderly of day care centers were invited by AIH to enroll in visits to HKMH on Tuesdays, during which the museum was closed to the general public. Each visit consisted of a guided tour and a subsequent art workshop related to the exhibition theme. Psychological wellbeing assessments were used to assess participants' mood, quality of life, and psychological wellbeing. Data was collected by various methods: questionnaires self-completed by caregivers, close-ended questionnaires facilitated by researchers to participants, and observational surveys conducted by researchers. The effectiveness and feasibility of Journey for Active Mind was

evaluated by comparing participants' assessment scores before and after the program, and by analyzing researchers' observations. Qualitative interviews were conducted by researchers to PWD and their caregivers to collect more in-depth opinion about the tour experience. The formats of the qualitative interviews were in mini focus groups or individual interviews, depending on the availability of the participants.

## *Assessment tools*

The following scales and questionnaires were used in the study:

### **1. Quality of Life Scale – Alzheimer's Disease (QoL-AD)**

Quality of life was measured by the Quality of Life - Alzheimer's Disease (QoL-AD). QoL-AD was a 13-item instrument specifically designed to measure the quality of life of people with dementia. Higher score indicated a better self-perceived psychological health.

### **2. Smiley-Face Assessment Scale (SFAS)**

Mood was measured by the Smiley Face Assessment Scale (SFAS). The scale consisted of a single question of the interviewee's on-spot mood, presented on a 5-point Likert scale in pictorial form, which represented "very sad", "somewhat sad", "neutral", "somewhat happy", and "very happy". Higher scores indicated a better mood.

### **3. General Health Questionnaire (GHQ-30)**

Psychological symptoms were detected by the General Health Questionnaire. The scale consists of 30 questions about the recent frequency of symptoms, such as "loss much sleep over worry", "been having restless, disturbed nights", and "felt constantly

under strain." Higher score indicated poor psychological wellbeing.

### **4. Supplementary Questionnaire - Set A (Set A)**

General perception towards the visit (11 questions) and participants' basic personal information (3 questions) were investigated by Set A. The supplementary questionnaire consisted of close-ended questions and was self-completed by elder participants without dementia.

### **5. Supplementary Questionnaire - Set B (Set B)**

General perception towards the visit (8 questions) and participants' basic personal information (2 questions) were investigated by Set B. The supplementary questionnaire consisted of close-ended questions, and was self-completed by an accompanying family caregiver of a PWD.

### **6. Supplementary Questionnaire - Set C (Set C)**

General perception towards the visit (11 questions) of PWD was investigated by Set C. The supplementary questionnaire consisted of close-ended questions, and was completed by an interview with PWD facilitated by a CUHK researcher.

### **7. Supplementary Questionnaire - Set D (Set D)**

PWD's basic personal information (5 questions) was investigated by Set D. The supplementary questionnaire consisted of close-ended questions, and is to be completed by an interview with a caregiver of PWD facilitated by a CUHK researcher.

### **8. Supplementary Questionnaire - Set E (Set E)**

General perception towards the visit (19

questions) and the caregiving participants' basic personal information (6 questions) were investigated by Set E. The supplementary questionnaire consisted of close-ended questions, and was self-completed by an accompanying family caregiver of a PWD.

## **9. Observational Survey**

Researchers conducted observation during guided tour and workshop to investigate the interaction between the PWD and the docent, caregivers and other elderly.

## *Data Collection and Analysis*

Questionnaires

### **1. Questionnaire for people without dementia (PWOD)**

People without dementia were given a set of questionnaire which consisted of two self-completed SFAS and were completed once immediately before the guided visit, and once after the art workshop, as well as Set A. The entire set was completed by the PWOD alone, while HKMH was responsible for questionnaire delivery, collection, and checking.

### **2. Questionnaire for people with dementia – Simplified version (PWD-SV)**

People with dementia who did not wish to participate in the in-depth research were given a set of short questionnaire which consisted of two self-completed SFAS and were completed once immediately before the guided visit, and once after the art workshop. On occasions that a family caregiver was present, the caregiver was asked to self-complete Set B. HKMH was responsible for questionnaire delivery, collection, and checking.

### 3. Questionnaire for people with dementia – Full version (PWD-FV)

Dyads who agreed to participate in the in-depth research were given PWD-FV.

People with dementia were interviewed four times. Before the first museum visit, QoL-AD and SFAS were conducted; after the art workshop on the first museum visit, SFAS was conducted. If PWD paid a second visit to the museum, SFAS was conducted before the second museum visit. QoL-AD, SFAS, and Set C were conducted either after the second museum visit, or within two months after the first visit. CUHK researchers facilitated all interviews.

Caregivers who accompanied PWD were given GHQ-30 before the first museum visit. Set E, which was self-completed, and Set D, which was conducted by interview facilitated by a researcher. Set E and Set D were given to the caregivers either after the second museum visit, or within two months after the first visit. CUHK researchers were responsible for conducting interviews for PWD-FV dyads.

### Procedures

Data collection was from November 2014 to May 2015. Subjects were recruited via day care centers in Hong Kong by AIH. Informed consent was obtained from eligible participants before the visits by AIH and/or before interview started. For PWD interview, before and after each visit, a researcher approached the research dyad and collect data. During each visit, the same researcher observed the communication pattern between the dyad and completed the observational questionnaire. Questionnaires for PWD-SV and PWOD were delivered by HKMH and self-administered by participants with help of HKMH staff.

### Analysis

The SPSS (Version 22) statistical software was used for data analysis. Data were processed to obtain frequencies, group mean values, and standard deviations (SD) where appropriate. Student's t test was used as significance test.

## RESULTS

### Demographic information of participants

The valid samples for various questionnaires completed were listed below:-

- PWD-FV:** 33 PWD completed PWD-FV pretests and posttests, 25 PWD caregivers completed PWD-FV pretests and posttests;
- PWD-SV:** 13 PWD completed PWD-SV elderly part, 12 PWD caregivers completed PWD-SV caregiver part.

- PWOD:** 653 PWOD completed the questionnaires.

In this report, the sample size of individual item might not be the samples collected as stated above because of missing data (i.e. individual item was not filled in by participants).

**Table 1** showed the demographic characteristics of the participants in this research.

**Table 1. Demographic characteristics of visit participants**

	PWOD (N=653) N (%)	PWD-SV (N=13) N (%)	PWD-FV (N=33) N (%)	CG (N=25) N (%)
<b>Gender</b>				
Male	167 (25.8%)	5 (38.5%)	13 (39.4%)	6 (24%)
Female	481 (74.2%)	8 (61.5%)	20 (60.6%)	19 (76%)
<b>Age</b>				
Below 49	-	-	-	3 (15.8%)
49-59	-	-	-	7 (36.8%)
60-69	189 (29.6%)	0	3 (9.4%)	4 (21.1%)
70-79	256 (40.1%)	3 (23.1%)	5 (15.6%)	0
80 or over	194 (30.4%)	10 (76.9%)	24 (75.0%)	5 (26.3%)
<b>Education</b>				
Never received any	147 (22.6%)	-	4 (12.1%)	
Informal education	31 (4.8%)	-	4 (12.1%)	
Elementary education	285 (43.8%)	-	16 (48.5%)	
Secondary education	156 (24.0%)	-	7 (21.2%)	
Tertiary education or above	31 (4.8%)	-	2 (6.1%)	
<b>Marriage</b>				
Single	-	-	-	6 (24%)
Married	-	-	14 (42.4%)	18 (72%)
Widowed	-	-	19 (57.6%)	1 (4%)
<b>Dementia stage (reported by CG)</b>				
Early	-	-	15 (46.9%)	-
Intermediate	-	-	17 (53.1%)	-
<b>Relationship to PWD</b>				
Spouse	-	-	-	8 (32%)
Children/children-in-law	-	-	-	16 (64%)
Others	-	-	-	1 (4%)
<b>Past experience in museum visit</b>				
Yes	489 (75.3%)	-	17 (53.1%)	20 (80%)
No	160 (24.7%)	-	15 (46.9%)	5 (20%)

Remarks: PWOD=People without dementia; PWD-SV=People with dementia (Short version); PWD-FV=People with dementia (Full-version); CG=Caregivers of people with dementia; Discrepancies between percentage and count were because of missing data.

### Emotional wellbeing of elder participants

Table 2 and 3 presented the assessment scores of participants.

#### 1. PWOD (N=639)

A significant increase in self-reported SFAS score among PWOD was detected. Participants had a mean mood score of 4.44±.026 out of 5 points before the museum visit, and an elevated mood of 4.72±.021 after the day's program. The increase in mood score reached statistical significance (p=.000).

#### 2. PWD (N=46)

PWD-SV (n=13) and PWD-FV (n=33) filled in SFAS scores and their results were combined for analysis. Participants had a mean mood

score of 4.00± .730 out of 5 points before the museum visit, and an elevated mood of 4.33± .732 after the program. The increase in mood score reached statistical significance (p<.05).

#### 3. PWD (N=13)

Thirteen PWD paid a second visit to the museum. There was a trend of increase in interviewed SFAS score among PWD on their second visit. Participants had a mean mood score of 4.00± .913 out of 5 points before the museum visit, and an elevated mood of 4.15± .689 after the day's program. A comparison of the mood changes in two visits yielded an insignificant decrease in the scale of elevation in mood.

Table 2. Self reported mood (First visit)

	PWOD (N=639) M(SD)	PWD (N=46) M(SD)	PWD-FV (N=33) M(SD)
Before museum program	4.44 (.03)	4.00 (.73)	3.85 (.76)
After museum program	4.72 (.02)	4.33 (.73)	4.21 (.78)

Remarks: PWOD=People without dementia; PWD=People with dementia (Short and full versions combined); PWD-FV=People with dementia (Full version).

Table 3. Self reported mood (Second visit)

	PWOD (N=639) M(SD)	PWD (N=46) M(SD)	PWD-FV (N=13) M(SD)
Before museum program	-	-	4.00 (.91)
After museum program	-	-	4.15 (.69)

Remarks: PWOD=People without dementia; PWD=People with dementia (Short and full versions combined); PWD-FV=People with dementia (Full version).

### Quality of life

Quality of life of PWD and PWOD reported before the first visit (N=33) had a mean score of 32.06 ± 5.87 out of 52 points. Quality of life reported after

the visit (N=33) had a mean score of 35.15 ± 6.62 out of 52 points. Comparison of means yielded a significant difference between the results.

Table 4. Self reported quality of life of people with dementia (N= 33)

	M(SD)
Before first visit	32.06 (5.87)
After second visit	35.15 (6.62)

Self reported psychological health before the first visit (N=25) had a mean score of 32.84 ± 8.34. Self reported psychological health after the visit (N=25) had a mean score of 35.36 ± 7.02. There was an insignificant trend of poorer psychological

health. The sub-domains showed that there were significant improvement in "anxiety" and "sleep disturbance" and significant decrease in "inadequate coping" and "social dysfunctioning".

Table 5. Self reported perceived health of caregivers of people with dementia (N=25)

	Before visit M(SD)	After visit M(SD)	Sig.
Total score	32.84 (8.35)	35.36 (7.02)	n.s.
Anxiety	6.28 (3.94)	5.92(3.59)	.000
Depression	2.40 (1.35)	3.16(1.95)	n.s.
Inadequate coping	11.56 (2.20)	14.40(2.08)	.012
Social dysfunctioning	9.48 (2.57)	10.80(1.32)	.014
Sleep disturbance	1.28 (1.37)	1.08(1.35)	.010

**Communication and engagement during tour visit and art workshop**

14 observations were done in the first visits and 7 were done in the second visits. Since only five dyads were observed twice, no within-subject comparison was performed.

Table 6 showed the communication pattern of PWD during the gallery tour in the two visits. Participants who were on their second visit

had less communication with the docent and other elderly, demonstrated less non-verbal communication with their family caregiver, and showed less positive affects. However, the number of times they initiated any verbal communication with their family caregivers increased. Improvement in communication between PWD and their family members were further explored in the qualitative research.

**Table 6. Engagement pattern of PWD during gallery tour on the visits**

	First visit (N=14) (M)	Second visit (N=7) (M)
Verbal communication with docent	41.21	19.29
Verbal communication with other elderly	4.50	1.57
Verbal communication with caregiver	41.36	58.71
Non-verbal communication with caregiver	14.07	11.86
Positive affects	23.93	11.43
Negative affects	0.93	0.57

Remarks: Engagement pattern was recorded by the number of times an observed participant initiated a verbal or non-verbal communicative action, or demonstrated a positive or negative affect.

Table 7 showed the communication pattern of PWD in the art workshop on both visits. On the second visit, participants were slightly less engaged in the conversation with the artist, but demonstrated slightly more willingness to communicate with other elder participants during the art workshop.

Similar to the communication pattern in the gallery tour, there was a trend of increase in verbal communication initiated by the PWD towards the family caregiver. The observed positive affects in the art workshop were also comparable between the two visits.

**Table 7. Engagement pattern of PWD in the art workshop on the visits**

	First visit (N=14) (M)	Second visit (N=7) (M)
Verbal communication with artist	10.93	9.43
Verbal communication with other elderly	1.00	2.29
Verbal communication with caregiver	28.93	35.86
Non-verbal communication with caregiver	9.79	4.14
Positive aspects	12.50	12.71
Negative aspects	0.57	0.29

Remarks: Engagement pattern was recorded by the number of times an observed participant initiated a verbal or non-verbal communicative action, or demonstrated a positive or negative aspect.

**Perception towards the museum visit**

**1. PWOD (N=652)**

Table 8 showed the evaluation of the PWOD. Respondents were overwhelmingly positive

towards the program. Most considered themselves likely to participate in future museum programs, but less were interested in handcraft-related activities.

**Table 8. Program evaluation by PWOD (N=652)**

	%
The content of exhibition was interesting.	99.4
The docent gave a clear presentation.	98.6
It was enjoyable to talk to the docent.	98.8
It was enjoyable to visit with other older people.	99.7
The environment was comfortable.	99.7
The art workshop was enjoyable.	98.5
I would share my experience with my friends and relatives.	98.5
I am interested in visiting the Museum of History again.	98.2
I am interested in doing handcrafts/ art works/ paintings in the future.	84.4
Overall, I was satisfied with the visit.	99.7

**2. PWD (N=33)**

Table 9 showed the program evaluation made by PWD. Participants with dementia generally found the experience satisfying, but motivation to future visits and workshops were slightly lower than elderly who did not have dementia. Further investigation was made during the qualitative

research. It was observed, however, that some participants were unable to make comments on specific elements of the program due to their forgetting about the details of visit (e.g. three respondents could not recall the docent, and thus could not comment on the clarity of his/her presentation).

**Table 9. Program evaluation by PWD (N=33)**

	%
The content of exhibition was interesting.	80.6
The docent gave a clear presentation.	96.7
It was enjoyable to talk to the docent.	96.3
It was enjoyable to visit with other older people.	96.8
The environment was comfortable.	93.3
The art workshop was enjoyable.	83.3
I would share my experience with my friends and relatives.	76.7
I am interested in visiting the Museum of History again.	78.8
I am interested in doing handcrafts/ art works/ paintings in the future.	75.8
Overall, I was satisfied with the visit.	96.7

### 3. PWD-SV- Caregivers (N=12)

Evaluations of the program made by the caregivers of PWD who contributed to the short version questionnaire were presented in Table 10. The overall satisfaction rate of the

program was overwhelmingly high. Room for improvements in the museum environment was noted by some. The specific reason for discomfort was further discussed in the qualitative session.

**Table 10. Program evaluation by caregivers of PWD (PWD-SV) (N=12)**

	%
<b>My family member enjoyed the museum visit.</b>	100
<b>My family member enjoyed the workshop.</b>	100
<b>The program facilitated the communication between my family member and I.</b>	100
<b>The program facilitated the communication between my family member and other people.</b>	91.7
<b>The environment was comfortable.</b>	83.3
<b>I am interested in participating in similar exhibitions with my family member.</b>	100
<b>Overall, I am satisfied with the visit.</b>	100

### 4. PWD-FV- Caregivers (N=25)

Table 11 showed a detailed feedback made by caregivers of PWD who contributed to the full version questionnaire. Most of the caregivers of PWD participated in the program because they wanted the person under care could enjoy a day out (92%). Slightly above half were attracted to the program because they wanted to engage in activities together with their family member (56%). These echoed the findings in the qualitative research as caregivers expressed how they saw

the museum program as a positive stimulation for PWD, and how they valued the quality time they share with their family members. Respondents had a satisfaction rate ranging from five to ten points (out of ten points), with a mean satisfaction score of 8.4. Most caregivers reported to find the program enjoyable (95.8%), and believed that their family members enjoyed the program (95.8%). Reasons for appreciation and expectations to future visits were further discussed in the qualitative research.

**Table 11. Program evaluation by caregivers of PWD (PWD-SV) (N=25)**

	N (%)
<b>Reasons for participation:</b>	
<i>I wanted my family member to enjoy a day out.</i>	23(92%)
<i>I wanted to participate in an activity with my family member.</i>	14(56%)
<i>I liked museum exhibitions.</i>	6(24%)
<b>The part I appreciated most:</b>	
<i>Interactions between the docent and the older participants</i>	8(32%)
<i>The presentation of the docent</i>	7(28%)
<i>The workshop</i>	7(28%)
<i>Nothing to appreciate</i>	3(12%)
<b>The part I disliked most:</b>	
<i>The arrangements of the visit</i>	3(12%)
<i>The workshop arrangements</i>	1(4%)
<i>The presentation of the docent</i>	1(4%)
<i>Interactions between the docent and the older participants</i>	1(4%)
<i>Nothing to dislike</i>	19(76%)
<b>I enjoyed the program.</b>	23(95.8%)
<b>I believe my family member enjoyed the program.</b>	23(95.8%)
<b>The exhibition content was interesting.</b>	24(96%)
<b>The docent gave a clear presentation.</b>	25(100%)
<b>I enjoyed visiting with older visitors.</b>	24(96%)
<b>I enjoyed visiting with other caregivers.</b>	24(96%)
<b>Benefits the program had to me:</b>	
<i>It improved my own perception towards my family member.</i>	14(56%)
<i>It allowed me a better understanding of my family member.</i>	14(56%)
<i>I have a more positive evaluation to the capability of my family member.</i>	13(52%)
<i>It gave me an opportunity to communicate with other caregivers.</i>	12(48%)
<b>Benefits the program had to my family member:</b>	
<i>My family member was happier after the visit.</i>	22(88%)
<i>It gave my family member an opportunity to communicate with others.</i>	17(68%)
<i>It made my family member more confident.</i>	12(48%)
<b>The environment was comfortable</b>	25(100%)
<b>The environment was suitable for a PWD.</b>	24(100%)
<b>My mood improved after the visit.</b>	16(64%)
<b>I will share my experience with my friends and relatives.</b>	21(84%)
<b>I am interested in revisiting the History Museum with my family member.</b>	23(95.8%)
<b>I am interested in participating in other visits with my family member.</b>	24(95.8%)
<b>I will consider participating with my family member in:</b>	
<i>Art workshops</i>	20(80%)
<i>Exhibitions in other museums</i>	18(72%)
<i>Activities other than exhibitions organized by the History Museum</i>	17(68%)
<i>Interest in revisiting the galleries of the History Museum</i>	12(48%)

Remark: Discrepancies between percentage and count were because of missing data.

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## Qualitative Research

Fifteen caregivers and five PWD participated in the qualitative research. Two mini focus groups involving five PWD and their caregivers were conducted, and the remaining caregivers were individually interviewed. The respondents aged from 47 to 87, with six males and 14 females.

### 1. Experience

Caregivers and PWD were generally positive about their museum experience. Many reported feeling an emotional uplift after the program, which echoed the findings from the quantitative research.

#### a. Gallery tour

Most caregivers and participants with dementia enjoyed the tour, and were most impressed by displays that related to their past experience. The majority of the caregivers and the participants with dementia thought the docent had a lively and clear presentation, which echoes the questionnaire findings. The way the docents engaged the audience was much appreciated:

*"The docents were professional in encouraging them. I found the interactions and the response from elderly participants impressive..... When he (the docent) talked about things in the past he would make an effort to attract them, such as mentioning the Jockey Club lottery tickets at the store (display), and because he was stimulating, the audience was quite willing to take the initiative to talk about 'I used to do such and such', and then the docent would say, 'wow, you were so cool.' I think the atmosphere was pretty good." (Daughter, 57)*

Some caregivers noted that their family members could not focus on the docent's

presentation for long, likely because some care recipients had a short attention span because of dementia. Some caregivers suggested that the docents could be more aware of the needs of people with dementia, and make adaptations in slowing talking speed, intonations, and making more emphases. Few caregivers also thought that elements such as a short documentary shown on big screen could draw attention to those who were less interested in listening to speeches.

#### b. Workshop

Most caregivers appreciated the workshop. It was mentioned that the workshop was able to engage those who had a relatively passive participation in the tour session, because the workshop gave them a specific task. Caregivers appreciated the opportunity to work on the artwork together and to show their love through offering help. Some caregivers pointed out that their family member seldom worked on handcrafts at home, but once being accompanied, they were happy to join in the activity. A few caregivers pointed out that they had displayed the artworks at home. The sense of achievement observed could be illustrated by a spousal caregiver:

*"We made a very beautiful object, a very pretty piece..... It's hanging in the living room now, and when people visited they said it was pretty. [My wife] told others that she made it..... Of course she was happy, she felt smart and proud." (Husband, 85)*

Caregivers had different comments about the artworks. Paintings and simple handcrafts, such as a water bottle sculpture, were much welcomed, and caregivers found the step-by-step instructions clear and easy to follow.

In contrast, a particular piece (paper mask), was commented to have involved abstract ideas and complicated techniques, therefore caregivers found it less suitable.

#### c. Schedule

The majority of the caregivers thought the duration of the tour and the workshop should not be extended, because their family members might feel tired and exhausted if the program lasted longer. Some caregivers who preferred a longer program remarked that a sufficient breaking interval would be needed to sustain the older people's energy.

Most caregivers expressed a wish to enrich the scheduled activities within the current time frame. They suggested that simple refreshment should stimulate positive mood from the people with dementia, and boost up their motivation to participate. Several caregivers also noted that the tour only covered one floor of the exhibition, and would like to see more in the tour. Intervals for the caregivers to communicate with each other, and simple exercise for the care recipients were also suggested as an add-on.

#### d. Special arrangements

The majority of the caregivers thought that visiting during the museum was closed to public could "make the environment quieter", "avoid visitors from getting lost", "create more space", and "facilitate management". It was mentioned that older visitors walked relatively slow, and it could be an issue to the tour if the galleries were too crowded. Several caregivers pointed out that the group was a "VIP" tour, and caregiver raised out that the arrangement could strengthen the idea of exclusion, but admitted that the family member did not seem to be

aware of it. In general, it was agreed that the arrangement facilitated better engagement:

*"It helped Dad concentrate, so that he would not look around [at other visitors]. Older people have poorer hearing, if the environmental noise is loud, they won't be able to listen well." (Daughter, 53)*

Most caregivers appreciated the shuttle bus service. It was pointed out that the shuttle bus saved the discomfort of transport transfer and outdoor heat, and therefore it could ensure the participants had a good mood from the start. For those who had difficulties in walking, the arrangement made the trip easier; for others, the point-to-point service allowed them to be more mentally relaxed:

*"[Without a shuttle service] I won't visit the museum, I fear he (the husband) may get lost. I don't use complicated means to get around..... I seldom go to the Kowloon side, with the shuttle bus, it was convenient." (Wife, 52)*

The arrival experience was confusing to some. One caregiver who drove to the museum said the signage was unclear, and since the family was unaware of the meeting spot, they walked to the main entrance to find it closed.

#### e. Environment

Aligning with the results in the questionnaire, caregivers generally found the museum comfortable. Caregivers thought the museum was spacious and well equipped with disable facilities. However, half of the caregivers also talked about their concerns in the lighting. It was remarked that in dim environment the participants tend to feel sleepy and had lower attention. Caregivers also pointed out that in carpeted area, more light is required to

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eliminate the risk of fall:

*"I think the biggest problem was his poor eyesight, he had a hard time looking at the display..... I think it's an issue of demented people, they don't like dark places, and [in such places] they begin to stumble."*  
(Daughter, 50)

#### f. Walking speed and walking load

Several caregivers thought the tour was slightly rush, and it was observed that the shape of the group was often long, making those who walked slow could not listen properly, and those in front had to spend much time waiting for others to keep up. It was commonly mentioned that the seating area was essential, and all people with dementia from the focus groups said they did not feel tired from the walking, which aligned with the observation of most caregivers.

## 2. Satisfaction

### a. Social gathering and quality time

The majority of the participants felt positive about the program. Most considered it an opportunity to spend quality time with their family members, and to show their love. A wife was grateful because her spouse was allowed to the program:

*"Bringing him along, so that I could see, and he could see too."* (PWD, female, 87)

Some caregivers found little chance to talk with each other because they were occupied to providing assistance to their family member in the tour and in the workshop, but others managed to talk on the way. A spousal caregiver described the interactions in details:

*"With other elderly, sometimes we could exchange our thoughts, and it felt good."*

*"You're bringing your family member, how does that feel?" "How is it with the daily caregiving?" [I could] feel it and listen to it, and talked to the others who provide care."*  
(Husband, 87)

### b. Reminiscence boosts communication

Displays which were associated to personal experiences, such as the herbal tea store and the old style convenience store, yielded highest rate of recall. During both focus group sessions, participants talked about events and landscapes from the past, and the same dialogue was said to happen in the museum gallery. The majority of the caregivers liked the exhibition theme, it was described that the displays stimulated an emotional resonance, and many were impressed by their family members when they were able to associate gallery exhibits to themselves, and shared information that were previously not discussed, such as childhood experiences. A wife specifically pointed out the transformation of her husband in the museum:

*"He seldom speaks unless I speak to him, and in usual days I mostly ask him what the date and the month are..... [In the museum] he kept talking as he walked, and spoke to me about the trade fairs, haircutting as a kid, and old things about the herbal tea shops."*  
(Wife, 66)

### c. Continuance

All caregivers agreed that the program was an enjoyable activity to their family members, and it was pointed out that "it was the process that mattered". Some caregivers reported that their family members had a brighter mood at home after the visit, and some even reported that the conversation about the visit lasted for several days:

*"Without seeing anything special and without outside stimulations, we sometimes fall into silence at home, but then after the visit there were three to four days in which we had new topics, Dad would talk about the rice stores and the herbal tea shops from the past."* (Daughter, 53)

## 3. Motivation

All but one caregiver said they were motivated to visiting other museums. One third of the caregivers mentioned that they would not revisit MH with their family caregivers because of the lack of novelty. One caregiver observed that her mother showed less interest to the exhibits on the second visit.

Some caregivers said the family members would be happy "as long as they have a day out", that "it was better to stay home", and

several saw the program as a stimulating activity such that the content did not matter.

One spousal caregiver said the following:

*"I think doing reminiscence there is good, recalling the past. He talked about the temporal housing settlements, and how the water restriction was carried out once in four days..... I feel that there are things that still exist in his brain.....he doesn't really mind what he does; he behaved similar in the two visits."* (Wife, 83)

One caregiver talked about the meaning she interpreted from the program:

*"To me, seeing him (the father) interact with others let me know that he isn't that bad, and I value the chance to spend time together, that was a chance to see him."*  
(Daughter, 57)

## DISCUSSION

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Both elderly participants with normal cognitive functioning and with dementia resulted in a significant elevation of mood after the visit and workshop. Those visiting the program twice experienced an elevated mood from the museum program but also with an insignificant decrease in mood between the visits, the small sample size did not yield conclusive analysis on this change, but the result indicated that one visit might suffice for elevating participants' mood.

Self-perceived quality of life of PWD also increased significantly after the visit, which, with regard to the qualitative results, might be attributed to the chance of having outdoor activities, reminiscing past lives by the gallery items, as well as doing artworks.

Self-perceived psychological health of caregivers insignificantly worsened after the two visits, in which two sub-domains "inadequate coping" and "social dysfunctioning" got a significant decline. This program was not a coping training, so it might not help caregivers to adopt coping in their lives, and the decrease indicated that they might need other intervention on this theme.

In qualitative interviews, some caregivers said that they engaged a lot taking care of their family members during the visit and workshop, and did not have enough time to chat with other caregivers, their engagement with their family members but not others might explain the decline in social dysfunctioning. On the other hand, there was significant improvement in "anxiety" and "sleep disturbance", this indicated that the program served its purpose in improving the psychological wellbeing of the participants, and this might help

ease the anxiety, therefore promoting better sleep, among caregivers.

The program, both visit and workshop, was shown to help facilitate communication between people with dementia and their family caregivers, about past experience, about finishing the handcraft etc. The caregivers valued the quality of life of their beloved with dementia, and wanted them to enjoy happy time outside their homes.

In addition, the handcrafting in workshop offered several elderly sense of achievement, which is often deprived of in life with dementia, and this also contributed to their better quality of life. This could be a powerful motivator for future programs to get caregivers involved, especially for the day care center users who are anticipated to have less leisure activities with their family caregivers.

The success of the program is also attributed to the theme, which allowed the elderly to reminisce and the caregivers to understand the past experience of the elderly. The lively presentation of the docents and artists, in particularly using examples of past time, also helped make the experience more positive. Slower talking speed and elevated intonation would further help keep the short attention of the elderly with dementia.

Sense of security was a major concern among caregivers, in this program, that the museum was opened to the program when it was closed to the public, as well as offering point-to-point transportation, served to give family caregivers this sense of security. On the other hand, the dim lighting in the museum lessened the sense of security, caregivers might worry about potential fall of the elderly.

## LIMITATION

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In spite of these encouraging findings, the small sample size prevented us from generalizing the findings to the entire population of people with

dementia. There was no control group in this study, so other variables that might affect the research results were not tested.

## CONCLUSION AND RECOMMENDATION

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The high satisfaction rates proved the success of the program in improving the psychological wellbeing of people with dementia by offering a good experience for people with dementia to have an outdoor activity reminiscing past events and making handcrafts, as well by offering an opportunity for people with dementia and their family caregivers to communicate.

The findings supported that one visit would suffice improving the psychological wellbeing of the people with dementia. Two visits might help verbal communication between the people with dementia and their caregivers, while the research findings were inconclusive in drawing benefits of two visits in other areas. In reality, people in Hong Kong were busy, it would be difficult for caregivers to arrange two visits with their family members.

Another suggestion for arranging tours for people with dementia was to make it when the

museum / venue is closed to the public. Caregivers explicitly expressed that such environment would make them feel more secure in carrying their usually vulnerable family members along. Point-to-point transportation was also welcome, particularly when elderly with dementia might be more vulnerable in terms of mobility and taking transport. In addition, offering refreshment would further motivate the elderly to participate.

Completion of handcrafts gives participants sense of achievement, so workshop is suggested to be kept, while for people with dementia, handcrafting with step-by-step instructions and less abstract ideas are more welcome. Further studies with larger sample sizes and control group would be warranted to provide more convincing evidence and help design an optimal art appreciation program for people with dementia.

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