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Perception and Experience of Macau COPD patients towards Self-Management

澳門慢性阻塞性肺病患者對自我管理的觀感與經驗

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Background 背景

- COPD is characterized by chronic airflow limitation which is due to narrowing and changes in the airway structures and collapse of alveolar.
  慢性阻塞性肺病是由於慢性氣道炎症而致**氣道結構改變或狹窄**，以及肺泡塌陷 *(ATS 2009, GOLD 2008, Reid & Innes 2010)*
- Cannot be cured, but can be prevented and treated
  不可以治癒，但它可以**預防**及**治療** *(ATS 2009, GOLD 2008, Reid & Innes 2010)*
- Contribute more to the global burden of disease in terms of disability-adjusted life years (DALYs) than other respiratory diseases
  預計慢阻肺比其它呼吸道疾病為**全球**造成更沉重的**疾病負擔**及更長的**失能調整生命年** *(Al I-Khaled et al. 2001)*
- In Macau, respiratory disease is the top three causes of all deaths in recent years.
  在**澳門**，呼吸系統疾病是近年三大死因之一 (澳門統計局, 2008).

Background 背景

- Self-management intervention is an approach that evolved throughout the 1990s in the West (Kaptein et al., 2009).
  自我管理干預在90年代在西方發展出來.
- Evidence that programmes providing self-management education are associated with improved outcomes ranging from the mastery of a particular skill to various dimensions of the well-being of the COPD patients (Lemmens et al., 2009, Effing et al., 2007).
  實證顯示自我管理教育干預可不同程度地提升個人生活技能，甚至生活質量.
- Literature searching on Medline, CINAHL and two major health related journals of Macau for the years 2001 to 2012 – no paper was found related to nursing care for these patients or self-management intervention for other chronic disease (SSM, 2002-2010; KWNC, 2002-2011).
  文獻查證(2001至2012年)**未能發現**本澳有關自我管理干預效果之研究報導
- Healthcare service provision for COPD focused on acute management
  本澳衛生服務則是集中於慢阻肺患者的**急性處置**

Background 背景

Self-management is defined as:

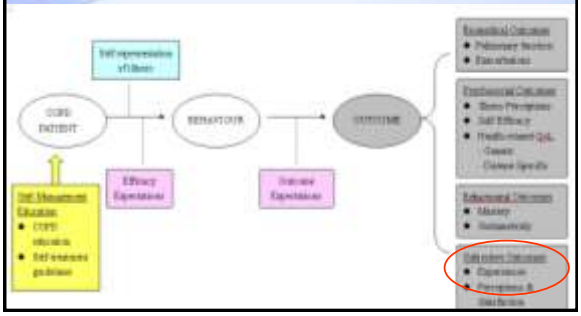
"*the active participation of the patient in the treatment of the disease based on sufficient coping behaviour, compliance with inhaled medication, attention to changes in the severity of the disease, and adequate inhalation technique*"

(Worth and Dhein, 2004, P. 267).

⇨ How do COPD patients in Macau perceive and adapt to a self-management approach?

Theoretical Framework 理論框架

自我管理教育對澳門慢性阻塞性肺病患者的影響 ~ 臨床探索性試驗



Research Aims 研究目的

- To explore the perception and experiences of Macau COPD patients towards self-management.
  探索澳門慢性阻塞性肺病患者對自我管理的觀感與經驗

Research Design 研究設計

An experimental design with a mixed methods approach
實驗性設計 + 混合方法進路

Methods

- Exploratory randomized controlled trial
  探索性隨機對照試驗 (MRC, 2008)
- Quantitative 量性 – Questionnaires
- *Qualitative 質性 - Focus group 焦點訪談小組*

(Barbour and Kitzinger, 1999)

Method of Data Collection 收集資料方法

- 3 Focus groups
- Purposive Sampling 目的性取樣
- Independent moderator 獨立訪談員
- Semi-structured topic guide 半結構訪談指引:
  i) perceptions and 對自我管理的觀感
  ii) experiences of the participants of self-management
  自我管理的經驗

Data Analysis 資料分析

- Thematic analysis 主題分析法 (Silverman, 2011)
  原始編碼→ 正式編碼 → 分類 → 副主題 → 主題 (Saldana, 2009)

Table 2 Characteristics of participants of the focus groups
焦點小組的參與者的一般狀況

Characteristics	Male 男性		Female 女性	
	Participate 出席	Not participate 不出席	Participant 出席	Not participate 不出席
Age < 60	–	–	2 + 1*	–
61 to 70	5	3	1	1
71 to 80	2	3	–	1
COPD classification				
Stage II	1	3	2	1
Stage III	4	1	1	–
Stage IV	2	2	–	1
Education level				
Illiteracy	–	–	–	1
Primary	5	5	3	–
Secondary	2	1	–	–
Tertiary or above	–	–	–	1
Living condition				
Live alone	–	–	1	1
With partner or children	–	2	1	1
With partner and children	7	4	1	–
Total	7	6	3 + 1*	3

* Family member

Main theme and sub-themes emerged from Perception and Experiences of Macau COPD patients towards Management 主題與副主題

Essentiality 必要性	
Helplessness 無助 - Miserable 痛苦 - Futility 徒勞 - Urgency 迫切 - Negligence 忽略	**Mutual Involvement 共同參與** - Individual obligation 個人責任 - Systematic level 系統參與 - Macro-level 宏觀參與
Support 支持 - Emotional support 情緒支援 - Knowledge input 知識學習 - Skills building 技能建立 - Treatment support 治療支持	**Control 控制** - Internalization 內化 - Agency 代理者 - Incapability 無能力 - Interference 干擾
Beneficial 有益的 - Bodily improvement 身體促進 - Functional improvement 功能促進 - Spiritual comfort 靈性安慰 - Individual difference 個人差異	

Essentiality 必要性

•必不可少的 或 絕對需要

Nick: 我哋**通過依個學習班呢就識得咩叫做慢阻肺囉, 以前就唔清楚我哋依啲病係咩病黎嗰囉**.

SL 哦…係呀

Nick: **以前我知道呀就咳啦, 多痰啦就..咪嗰啲熱氣**呀嗰啲情況, 咁呀自從學習依啲學習班之後就知道依家呢係叫做慢阻肺. [A116,8]

Wilson: 咁如果你未..未有學習班之前你唔知道…嗰身體點樣去控制佢架嘛…家陣時有學習班呢點樣點樣教你…吓…你自己雖然係唔…唔…唔…識得, 你有多少啦你都知道咁既情況…吓, 你都跟佢去做架嘛…咁身體比較好囉. **如果你唔知道, 盲朦朦咁你唔知係點樣咁..邊癈好**. 知道佢係有學習班, 知道點樣好咯, 咁咪照會做囉…哈哈.. [A941,14]

Helplessness 無助

Helplessness 無助 – Miserable 痛苦

Nick: … 依家有依啲病好辛苦架我覺得呀, 第一個就自己冇經濟來源架啦, 你..你**有親呢啲病唔做到嘢架啦, 你想做都唔得架! 你自己有錢都執唔到架真係, 冇辦法架啦!** 我有時咁樣喘番落黎, **一(蹲)落去就喘架啦**, 依家嚴重到咁既程度, 有時啲高啲嘢唔得就唔得.

[Ivan: 唔用得力架]

Nick: …唔用得力呀, **我從來唔攞到嘢架**. 有時我去新苗之嘛, 好近我屋企, 喺嗰度..我買啲廁紙, **買啲嘢揸住喺手, 夾梗上電梯嗰度都喘氣呀**. [A834,GD]

Helplessness 無助 – 徒勞 & 迫切

Lavin: 如果當初我未入黎去接觸伍姑娘之前, 咁依個病經常都要發作, 咁經常發作之後呢, 咁呀…隔離咗右幾廿歲呢, 就所謂咩呀mud 捽背脊呀, 一陣**攞啲薑捽吓背脊**呀之如此類. [B284,7]

Nick: 都要架, 都起碼好多知識你都要知架嘛, 依啲**唔係個個都知道呢個病, 起碼都要人了解要人識**, 依家有啲技巧呀, 營養點樣處理呀, 發病嗰時點樣臨急嗰時點樣, 都有個知識呀.

[Leon: 啫..啫姑娘…**啫都有個人介紹比我哋認識嗰病情係點樣, 又點樣去自己適應**, 幾好架.] [A1101,GD]

Helplessness 無助 – 迫切 & 忽略

Lavin: **我亦都希望你哋繼續做落去, 因為還有啲病人呢未…未知道**

Karen: 搵多啲新病人返黎囉…嘻嘻..

Christ: 真架, 呢個係真架.

Lavin: 或者好多唔知, 或者唔知

[Leon: 依家睇見喺啲公園呀, 有啲呀叔呀伯呀婆呀好多]

Lavin: …有啲人如果係知架呢…學吓呢, 的而且確係有幫助既. [B1333,GD]

Lavin: **真係好辛苦, 因為你唔識得去問人, 學呼吸嘛**. [A417,7]

Mutual Involvement 共同參與

Mutual Involvement 共同參與 – 個人責任

SL: 咁你覺得依啲嘢係護士要做架?

Ivan: 都唔一定架……

(Nick: 哈哈哈)

SL: 唔係一定呀!?...點解呀?

Ivan: Errrr……..**你自己唔去…唔去照顧自己, 姑娘點樣教你都冇用啦**.

SL: 啊…咁樣. 你覺得個照顧責任係自己大啲.

Ivan: 係..自己.

SL: 或者有冇有其它意見架, 或者呀區女仕呀?

Amy: 我都一樣, 照樣, 呀伍姑娘教咗你, 你自己唔去理埋, 咁啫教你冇用. [A1110,GD]

Mutual Involvement 共同參與 – 系統參與

Leon: 如果咁樣呢…啫你哋本身…啫你哋**兩間醫院黎講呢啫抽一啲…..啫護士好醫生好咁樣出黎…啫全面負責依個咁既工作咁**呀..好囉

Chris: 呀..你依個都幾好… [B1415,GD]

Mrs. Lee: 係咪可以要求醫護..

[SL 係呀, 依家就係比一個空間你哋可以講囉]

Mrs. Lee: 啊..我就想…如果係…我都好驚…因為拿..幾時突特發咗之後呢…**我成日都諗..我心諗, 啫大咭利是一句(敲柏) 點算呢咁**? [C688,17W]

Mutual Involvement 共同參與 – 宏觀參與

Chris: **政府主導及重視**好緊要! [B1582,15]

Ivan: 慢阻肺個起源都係…最主要都係食煙, 我覺得, 係咪呀..係咪呀? 應該係啦.

Nick: 食煙係一部份啦.

Ivan: 依啲咁既情況呢, 應該政府呢比較多啲宣傳, 叫啲人戒煙呀!

SL 叫啲人戒煙, 叫啲人唔好食煙. 好呀. 哦, 係呀係呀. 喺你哋患者既角度到講出黎.

Ivan: 喺**我哋依家有啲咁既病情之後呢…真係…感覺到食煙..真係好壞好壞!** [A1140, 19]

Support 支持

Support 支持 – 情緒支援

Nick: 都幾好架, **好關心我哋**呀. 我啲病人有啲嘢都唔識呀.. [A854,8]

Mrs. Lee: 哈…**有時…我真係..我仲辛苦過佢 (笑中帶淚)**

[Winnie: 喘起上黎真係唔咩架]

Mrs. Lee: 又唔敢問, 問佢又唔答, 但你又唔知點樣可以幫到佢手. [C516,17W]

Support 支持 – 知識學習 & 技能建立

Amy: 哦, 教既內容….咁我哋初初都唔識呢, 咁**梗係教我哋先會知架嘛**咁樣囉 [A237,10]

Nick: 咁呀自從學習依啲學習班之後就知道依家呢係叫做慢阻肺 [A109,8]

SL: 學到啲mud嘢呀?

Lavin: **學到呼吸啦**

SL: 學呼吸, 點呼吸呀?

Lavin: 呀….用鼻吸囉…用咀呼囉, 咁慢慢黎呼架囉. 咁加上粗重嘢唔好抽啦…呀…**唔好抽啲粗重嘢, 唔好'扒'住太耐**, 太耐又會頂到條氣管. 咁呀. [B296,7]

Support 支持 – 治療支持

SL: 咁你覺得吸藥技巧喎..er..喺學習班裡面你哋又掌握到啲咩內容呀?

Karen: 啫佢教我..以前我吸得個咀呢…佢話**我接得嗰個嘢唔實囉, 就唔嚴囉, 有漏氣囉, 啫啲咗啲藥囉**.

Lavin: 我間中都會有, 自己吸既時間呢就睇住有少少上, 佢教我用盡力呀, 用盡個咀唇'目及'住嗰個

[Karen: 要接實佢囉]

Lavin: 咁呀係試過. 阿兒((女兒))都鬧咗我幾次 (笑).

SL: 哈哈….啫吸入既技巧要正確. 喀喀, 你哋最記得既呢樣嘢, 或者鐘生呢你有冇一啲印象深刻既內容呀? 啫吸藥既方法

Chris: **依個好重要架, 你駛用得唔好就等如零**呀. 所以呢個……..處理嗰時處理得唔好呀, 我初初…攞返去都唔……**後尾經過學習班至知道…唉! 原來我啲咗好多功夫. 唔怪得成日生痱子! 原來吸完冇漱口, 成日生痱子, 哎喲…好陰公! 就啲咗成幾個月時間**.. [B828,GD]

Control 控制

Control 控制 – 內化

Lavin: 我最差有一次呢出去拱北…出去拱北呀, 咁呀自己呢出去買啲嘢咁, 咁就氣促呀, 但氣促之中呢我諗番轉頭喎…挨住响度, 挨住响度就唔好'mou'低, 唔好爬住, 挨住响度呼吸(*演示: 呼吸*), 咁就抖完呢我就跟住攞支嘢黎噴嘞, 噴咗之後冇幾耐呢..咁樣就ok囉, 就冇咁…冇咁辛苦囉. [B511,7]

Control 控制 – 代理

Ivan: 我..我喘既時間好少, 我係..係上斜路, 係..係上梯級. 一到喘既時候我自己停一停, 唔怕架嘞, 冇事.
Nick: 都唔係好嚴重.
SL: 呀…所以喘既時候停一停, 同呀區女仕一樣.
Ivan: 我就冇吸嗰啲氣, 嗰啲飛碟嗰隻大概我都係**兩日吸一次囉**.
SL: 哦, 兩日吸一次.
Amy: 我就一日用兩次.
Nick: **規範用係一天兩次**.
Ivan: 我喘既時間真係好少, 係上梯吸先會有少少情況, **唔係好嚴重**. [A657,GD]

Control 控制 –無能力 & 干擾

Lavin: 一頭霧水呀…點點點郁 (在搖動雙手)
[Leon: 我哋**冇記憶**! 我同佢一樣嘞, **小學都未畢業**個咯]
[Karen: 咁我都係啦, 我都係啦]
Lavin: 講到我亂晒龍.
Karen: 我哋以前喺鄉吓呀嘛.. [B631,GD]

Lavin: **咁試過好多次都突然之間黎**, 啫有時啲空氣呀, 或者**天時轉變**呀, 咁嗰個肺部呢..就好自然會促架嘞. [B316,7]

Beneficial 有益的

Beneficial 有益的 – 身體促進

Lavin: 我就最深刻係呼氣, 吸氣囉, 對**肺功能好啲**囉.
SL: 哦, 呼吸, 吹出黎嗰呼吸, 都係, 對個肺功能好啲…哦…有啲咩原因你會覺得..啫有個咁樣既感覺既?
Lavin: 啫感覺到呢..你喺長期, 依家深呼吸對個肺部呢, **擴張好啲**; 以前食煙既時間呢, 肺部呢吸落去唔得話肺功能會擴大, 依家係好咗架, 可以**深呼吸嗰個胸部會擴大, 自己感覺到**. [A321,7]

Beneficial 有益的 – 功能促進

Lavin: 總之平時都吸架, 晚黑都…晚黑訓醒都係咁樣呼格…都係咁樣練習, 有時行路都係咁樣練習, 咁樣呢就..的而且確對個肺係幾好既. **我平時呢…行大概….半層樓梯都唔夠, 依家行4, 5層咁上吓**.
[SL 嘩..咁犀利呀. 啊..好喎好喎]
Lavin: 真係, 真係掙好遠
[Chris: (*鼓掌*) 好叻好叻!]
Lavin: 唔係講笑!
[Karen: 唔係…呼吸嗰樣嘢真係幫助好大]
Lavin: 可以話真係架依吓嘢呀, **我平時呀…嗱, 上黎鏡湖嗰個急….嗰個門診嗰度呢…行上二樓呢, 好辛苦吓! 啲仔女黎扶住上架, 依家我自己一個人行成4, 5樓都得**
Chris: 叻啦叻啦! [B419,GD]

Beneficial 有益的 – 靈性安慰

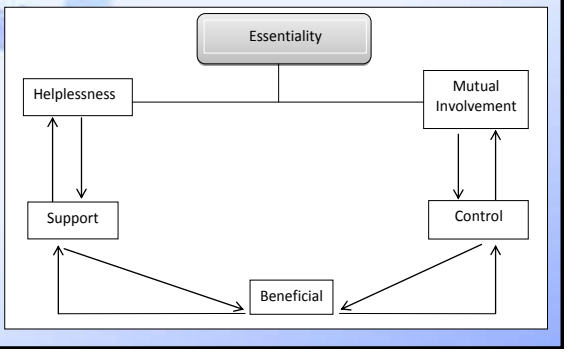
Chris: **本來等死**格, 冇啦呢次冇嘞呢次, 今次照計生命就係行到咁多架啦, 認命把啦…!! 咁樣學習班呢, 學咗好多嘢, 將嗰啲理論實習…啊…果然有效喎! **我仲有幾年命喎, 我仲可以做埋我想做啲嘢喎**. 所以依家呢我喺屋企都好, 仔女面前都好, 係老婆面前都好, 我想做咩佢哋比我去做. [B506,15]

Beneficial 有益的 – 個人差異

Nick: 要架….因為依啲嘢自己自理就最好架啦, 咁你發作起黎有時自己冇辦法架嘛….. 有時你唔得架嘛. **呢啲病一嚴重你就唔得架嘞**, 一喘氣嗰陣時你自己都唔掂, 你仲話去點做, 冇得做架.

Lavin: 當你放平呼吸唔到
[Karen: 辛苦嗰時唔得架]
[Chris: 要高少少!?]
Lavin: 嗰背同嗰呼吸暢順啲.
[Chris: 哦!]
Lavin: 再嚴重啲就’ gut’高少少
[Leon: **犀利得滯呢有啲時候開把風扇**...啫伍姑娘教既]
Lavin: 因為你個肺部呢’ un’住佢, 就冇個空間比佢.
Karen: **嗰啲((開風扇))就一個個人既體質**. [B1230,GD]

Relationship of Main theme and Sub-themes



Conclusion 結論

- **必要性**從參與者的觀感、體驗及期望中顯現出來
- 自我管理並非必然得到的, 是需**不同層次共同參與**才能實現的
- 受個人能力、個體差異及外在因素干擾會影響自我管理教育活動的效果
- 自我管理教育應在病人病情發展至**重度以前給予**, 並需**重覆進行**
- 應重視**控制呼吸**的指導, 用藥方面**與醫生採共識指導方案**
- 這有助提升護理服務質量, 提升治療效果及COPD病人活下去的信心

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Thank you!!

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