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PEER SUPPORT: DOES IT HOLD THE KEY TO DECREASING SELF-STIGMA AND IMPROVING SELF-MANAGEMENT IN OLDER WOMEN WITH URINARY INCONTINENCE?

Hypothesis / aims of study

Up to 55% of women living in the community experience urinary incontinence (UI). Of these, 20 to 25% have severe symptoms (>10 episodes/week). UI is a serious medical condition with significant negative impacts on overall quality of life. While most older women want to maintain social contact with family and friends, UI can compromise physical activity and functional independence, restrict social functioning and induce elevated levels of anxiety and stress.

One factor that can influence the experience of UI is the stigma associated with diagnosis and symptoms. Individuals are stigmatized when they possess, or are thought to possess, an attribute or characteristic that conveys a social identity that is devalued in a particular social context. Some individuals direct prejudicial attitudes inward, a phenomenon known as self-stigmatization. In Western societies, the elimination of bodily waste is a private matter that is done in a tidy way. Failure to do so risks being perceived as '*different*'. The onset of UI is often accompanied by embarrassment, elevated stress, and shame. It is common for individuals with UI to withdraw from social activities due to self-stigmatization [1]. A recent meta-analysis demonstrated that social disconnectedness in seniors is as detrimental to health and predictive of mortality risk as obesity and lack of physical activity[2].

Some have suggested that the incorporation of support from peers with similar health issues might be a way to better address the rehabilitation needs of clients and to diminish the self-stigma associated with age-related health conditions. Some of the key functions of peer support are: (a) assistance in daily management of health conditions, (b) social and emotional support, and (c) providing continued support over time as the condition changes. The purpose of this study was to assess how peer support for older women with UI might influence the self-stigma associated with UI and self-management of the condition. This could inform how current interventions might be adapted in order to prevent social disconnection among seniors with UI.

Study design, materials and methods

To understand the stigma associated with UI in older women and the influences of peer support, we conducted 8 semi-structured qualitative interviews, with a subset of women who participated in a 12-week group Pelvic Floor Muscle Training (PFMT) program for UI. The PFMT program was delivered to groups of eight participants in a weekly 60-min exercise class by an experienced physiotherapist. All participants in the study were aware that their peers shared the same condition. Each session included a ten-minute education period, a 30-minute session of PFMT in different static positions such as lying, sitting, four-point kneeling and standing feet apart and a 20-minute dynamic PFMT (dance). Participants were also given a PFMT to do at home, 5 days per week. To be included in the present study, women had to: be aged 60 or older; present symptoms of stress or mixed UI; have completed the 12-week group PFMT and have consented to an individual interview. Women were excluded from the project if they had a cognitive or communication condition that made it impossible to participate in interviews. A trained interviewer with knowledge of UI and stigma conducted the interviews. All sessions were audio recorded and transcripts of the sessions were analyzed using content analysis [3].

Results

The women interviewed were aged 60 to 77 years old (68 ± 5.26 years) they had been living with mixed UI for the last 2 to 36 years (11.13 ± 13.04 years). Before the PFMT, the average number of urine loss episodes on a 7-day urinary diary was 20.50 ± 28.47 episodes per week and the self-diagnosed severity through the ICIQ-UI SF questionnaire ranged from 7 to 16 (11.75 ± 3.99).

Participants described UI as a social problem. They stated that others see UI as a taboo subject, endorsing stereotypes that describe UI as dirty, abnormal, a female issue and an aging issue. Participants reported that the stigma surrounding UI is hard to break and they thought that UI is a subject that should be openly discussed. Overall, the 12-week PFMT provided the participants with 1) indirect peer-support, 2) direct peer-support that helped in daily management of UI and 3) the opportunity to disclose UI (within the group and outside of it).

1) Indirect peer-support: Knowing the other participants had UI removed the need to explain/discuss UI and may have reduced efforts to conceal the condition. Whether they use the support or not, knowing that peer support is available is comforting. Simply being in the class with peers provided women with the opportunity for social and emotional support. Participants indicated that they no longer felt alone with this condition, and felt a sense of belonging with other group members. Additionally, within the group the stereotypes associated with UI (e.g. people with UI are dirty) were demystified and not perpetuated. Rather, group members described one another as "pretty, dynamic and intelligent women".

2) Direct peer-support: The group provided the opportunity to talk about UI and gave the occasion to learn from common experiences. Participants appreciated sharing self-management strategies, tips and tricks that might not have been addressed if they were not in a group of their peers. In some cases, comparing oneself to others (i.e., condition severity) fostered empathy for others which could lead to compassion for self. For certain individuals, these comparisons made them realize that UI has varying levels of severity and that their problem may not be the worst, leading to diminished self-stigma and improved self-image.

3) Opportunity to disclose: Directly addressing UI in a group setting facilitated disclosing information about diagnosis and symptoms within the group and outside of the group. Disclosing within the group was described as less threatening since all the

participants were in attendance for the same reason. Likewise, group members referred to being empowered by other participants and be more prepared to share and discuss UI outside of the group.

Interpretation of results

We are cautiously encouraged by these findings. Our data analyses support the notion that peer interactions may provide social and emotional support to older women with UI, which may diminish self-stigmatization and help improve self-management strategies. It may be reasonable to think that these types of psychosocial benefits could serve to prevent social disconnection among community dwelling women. Nevertheless, it is prudent to state that these are preliminary findings and this study is ongoing.

Concluding message

Our study suggests that direct and indirect peer support from group training can influence the decision to disclose UI, and may aid in reducing self-stigma and in improving self-management. Peer interactions may help diminish self-stigma by giving opportunities for social and emotional support, providing assistance in daily management of UI and support during group rehabilitation. Support outside the group may carry forward over time.

References

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Disclosures

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RCT: Yes **Subjects:** HUMAN **Ethics Committee:** Research Ethics Committee of Institut Universitaire de Gériatrie de Montréal (CER IUGM 12-13- 002), Centre Hospitalier de l'Université de Montréal (CE12.347), Centre Hospitalier de l'université de Sherbrooke (#12-170-M5). **Helsinki:** Yes **Informed Consent:** Yes