Title Page

The support needs of patients waiting for publicly-funded bariatric surgery – implications for health service planners

Running head

Waiting for bariatric surgery

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Original contribution

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18 October 2016

Dear Professor Finer

Re: COB-16-OA-0058 “The support needs of patients waiting for publicly-funded bariatric surgery – implications for health service planners”

Thank you for the opportunity to revise our manuscript. We have carefully considered the reviews and have made amendments accordingly. Changes to the manuscript have been highlighted as requested. We confirm that the revisions have been approved by the co-authors.

We look forward to hearing from you.

Yours sincerely,

Professor Douglas Ezzy

(on behalf of all authors)

What is already known about this subject?

- Publicly-funded bariatric surgery can be preceded by long waits. To date, few studies have investigated the experience of waiting for bariatric surgery and all are Canadian.
- These studies highlighted that waiting for publicly-funded bariatric surgery in Canada can be emotionally difficult, may be associated with declining health and some people die from obesity-related disease before receiving surgery.
- A 2010 systematic review of bariatric surgery economic studies (n=11) and clinical trials (n=63), identified that data was lacking on the economic, clinical, and psychosocial consequences of long waits for bariatric surgery.

What does your study add?

- Lack of communication from those managing the waitlist appeared to add to the emotional burden of waiting for bariatric surgery. For example, patients reported feeling angry and frustrated and disillusioned with the system as a result.
- Gaps in peer and health professional supports appeared to contribute to declining psychological or physiological health while waiting for surgery (e.g. the worsening of or development of new obesity related comorbidity or weight gain).

Abstract

Objective: To investigate the experience of waiting for publicly-funded bariatric surgery in an Australian tertiary healthcare setting. *Methods:* Focus groups and individual interviews involving people waiting for, or who had undergone publicly-funded bariatric surgery, were audio-recorded, transcribed and analysed thematically. *Results:* Eleven women and six men engaged in one of six focus groups in 2014 and an additional 10 women and nine men were interviewed in 2015. Mean age was 53 years (range 23-66), mean waiting time was six years (range 0-12) and mean time since surgery was 4 years (range 0-11). Waiting was commonly reported as emotionally challenging (e.g. frustrating, depressing, stressful) and often associated with weight gain (despite weight-loss attempts) and deteriorating physical health (e.g. development of new or worsening obesity-related comorbidity or decline in mobility) or psychological health (e.g. development of or worsening depression). Peer support, health and mental health counselling, integrated care and better communication about waitlist position and management (e.g. patient prioritisation) were identified support needs. *Conclusion:* Even if wait times cannot be reduced, better peer and health professional supports, together with better communication from health departments, may improve the experience or outcomes of waiting and confer quality of life gains irrespective of weight loss.

Introduction

The provision of bariatric surgery has been increasing worldwide as an effective treatment for obesity and associated comorbidity (1). It is generally considered for adults with resistant class 3 obesity (body mass index (BMI) ≥ 40 kg/m²) or resistant class 1 or 2 obesity (BMI 30-34.99 and 35-39.9 kg/m² respectively) combined with specific obesity-related comorbidity (2, 3).

In the period 2011-12, approximately 4 million adult Australians or 27.2% of the adult population were estimated to be obese (4). Despite obesity being more prevalent in areas of socio-economic disadvantage (4), access to publicly-funded bariatric surgery is limited in Australia (<10% of bariatric surgery is publicly-funded) and like elsewhere (e.g. Canada) there is evidence of prolonged wait times (5-7).

Only a few studies have investigated the experience of waiting for publicly-funded bariatric surgery and all were Canadian. These studies highlighted that waiting (average wait time in Canada was estimated at >5 years in 2007 (5)) can be emotionally difficult, that it may be associated with declining health and that some people die from obesity related comorbidity whilst waiting (5, 8-10). Although in another Canadian study, a 1.5-2 year wait period did not result in notable weight gain or cardiovascular morbidity in 150 participants (11). A 2009 systematic review of 27 studies on the patient perspective of waiting for any type of elective surgery (principally coronary artery bypass graft, joint replacement and cataract surgery), concluded that the experience of waiting was not fully understood (e.g. the association between waiting and ill-health) (12). A 2010 systematic review of bariatric surgery economic studies (n=11) and clinical trials (n=63), identified that data was lacking on the economic, clinical, and psychosocial consequences of long waits for bariatric surgery (13).

Consequently, the objective of this study was to investigate the patient experience of waiting for publicly-funded bariatric surgery with a particular focus on the support experience and needs of patients, in an Australian tertiary public health setting, in the island state Tasmania. Tasmania has two public hospitals that conduct publicly-funded bariatric surgery (principally laparoscopic adjustable gastric banding (LAGB)). As at December 31, 2013 there were 204 patients waiting for this service, and on average 20-30 primary procedures were conducted annually in the period 2010 to 2014 (Personal communication, MH, Director of Monitoring, Reporting & Analysis, Department of Health and Human Services, Tasmania).

Methods

Design

Qualitative methods, in particular focus groups and individual interviews, were selected because they are the best practice methods for examining individual meanings and experience (14-16). Focus groups provide data on shared group understandings and practices, while individual interviews enable more detailed analysis of individual meanings (15, 16).

Semi-structured focus groups (up to 1.5 hours in duration) were conducted in 2014, involving individuals who were waiting for or who had received publicly- or privately-funded bariatric surgery. This study was concerned with only those who had taken a publicly-funded pathway because of the associated long wait for publicly-funded surgery. A focus group proceeded if several people with the necessary similar characteristics expressed interest in participating. To enable deeper exploration of important themes that arose in the focus groups relevant to health service planning (e.g. the physiological and psychological impact of waiting, support experiences and current health-related behaviours) questions were included in the first tranche of a series of interviews involving people who were waiting for or had undergone publicly-funded bariatric surgery in 2015. The interviews (approximately 20-30 minutes in duration) involved those who had not participated in the focus groups and who were waiting

for or who had received publicly-funded bariatric surgery in 2015. The focus groups were separated by sex and surgery status to explore potential differences. Written informed consent was obtained from all participants. Ethics approval was granted by the University of Tasmania's Health and Medical Human Research Ethics Committee (Reference number H0014039).

Recruitment

For the focus groups, the study was advertised in the Royal Hobart Hospital, Tasmania, three state newspapers and through radio interview. Using a stratified and randomised approach, letters were sent to publicly-funded LAGB recipients (n=127) and those waiting for surgery (n=185) by the Department of Health and Human Services through author MH. The sample was stratified in order to ensure a range of key subgroups of patients were included in the focus groups. Sampling was also randomised in order to avoid oversampling from categories that we knew were particularly numerous (e.g. females who had been waiting for surgery for more than three years compared with less than years or females who had undergone publicly-funded bariatric surgery compared with males). Additionally, SW provided interested and eligible patients with the study's information sheet. For the individual interviews, the study information was posted to potential participants or provided at pre-operative appointments by clinic staff.

Procedure

At initial contact, prospective participants were provided with an overview of the study. Information was collected on demographic (e.g. age, sex) and clinical characteristics (e.g. weight, height, time since surgery, time on waitlist) of those who expressed interest in participating and used for subsequent purposive sampling to ensure the inclusion of a range of key subgroups.

To ensure consistency in the collection of data, one author (MS) participated in or led all focus groups and another (KJ) oversaw or led all individual interviews. The discussion schedule for the focus groups and individual interviews focused on: weight and health status and change during the wait, support received or needed during the wait, communication received about the wait process, health related behaviours during the wait and how the experience of waiting could be improved. Interviews were conducted by telephone, except for one that was conducted in person.

Data analysis

The discussions were audio-recorded, transcribed verbatim and de-identified. Thematic analysis focused on the experience of waiting and was conducted using the software NVivo 10 (QSR International, Doncaster, Victoria, Australia). Other investigators also familiar with the transcripts, confirmed the emerging themes through regular discussion and reflexive consideration of the analysis. All quotes cited below are from participants. An audit trail was kept for the project that included transcripts, question schedules, memos, notes on research team meetings, a project logbook and reflective notes.

Results

Forty-six adults aged over 18 years who had received or were waiting for publicly-funded bariatric surgery expressed interest in participating in the focus groups and 25 in the individual interviews. Six focus groups were conducted between September and October 2014 and included 17 participants. Three focus groups were held in Hobart (the largest city in Tasmania with a hospital operating at the highest teaching and referral level) and three were held in Launceston (a smaller regional city with an accredited teaching hospital). Nineteen, individual interviews were conducted between May and November 2015. Additional

interviews were considered unnecessary because data analysis indicated that no new themes were emerging, suggesting that data saturation had been achieved. A summary of the clinical and demographic characteristics of participants (n=36) are provided in Tables 1 and 2.

The psychological impact of waiting

The discussions amongst both men and women indicated that waiting was commonly emotionally burdensome (Quote 1, Table 3). Although the negative emotions of waiting were discussed by some post-surgery participants, this theme was stronger amongst those still waiting for surgery. Emotions experienced during the waiting period were reflected in expressions such as: *desperate, worried, frustrating, depressing, given up, stressful, gets you down, just want it over and done with, anxious, and languishing*. One participant said she experienced headaches because of stress associated with waiting and another felt that his depression would have been less severe if the wait had been shorter. Another male said that whilst waiting he “*was in a fairly self-destructive mode mentally. I was quite happy to eat myself to death*” (post-surgery male, wait 4 years). A few participants (both men and women) spoke about the emotional impact of not being able to lose weight or from gaining weight during the wait (Quote 2, Table 3). Some women in the waiting list focus groups felt “*no one cares*” and that they were being unfairly blamed for the situation they were in (Quote 3, Table 3).

For many participants a lack of information provided to them or to their general practitioner (GP) about wait list position and expected time until surgery, appeared to have negative emotional consequences (Quote 4, Table 3). Only two participants said that they were given specific details about their waitlist position when they enquired. The frequency of communication reported to have been received by participants from the health department or hospital, ranged from annually, to a few times over an extended wait period (e.g. 12 years), to

no communication. Some participants felt uncertain about whether they were still on the waiting list because of a lack of correspondence from the department. One participant said he was told by the hospital that he was no longer eligible for surgery because he “*was too old and ... didn't have diabetes*” (waitlisted male, wait 6 years), but was later contacted to attend a pre-operative appointment.

Further, there were numerous accounts of a discordance between how long participants were originally told they would wait and how long they had been waiting. For example, one male said he was told the wait would be two to three years and he was now into his eighth year. Three participants talked about receiving a pre-operative appointment and subsequently anticipating surgery in the near future which did not occur (Quote 5, Table 3).

It appeared that the longer the wait, or greater the discordance between the expected and actual wait time, the more disillusioned with the system some participants became.

Discussion in the waiting list focus groups indicated suspicion of the management of the wait list, inferring dubious practices, such as the waiting period being unnecessarily protracted so that people became ineligible for the surgery because they were “*too old or too sick*” (waitlisted female, wait 2 years). Others could not understand how they could not be a priority for the surgery given their circumstances (Quote 6, Table 3). Another said he was told that he was an urgent case because “*Your diabetes is going to kill ya unless you get this weight off*” (waitlisted male, wait 7 years) and five years later he was still waiting. One participant reported that during the fourth year of waiting her level of prioritisation for surgery was actually reduced because she had lost weight. Participants said it would benefit them emotionally if more realistic information was provided. This benefit seems likely given that those participants who were told to expect a long wait were less likely to describe waiting as a negative emotional process. Two post-surgery female interviewees who had

waited four and five years said waiting had not been a negative experience (Quote 7, Table 3). One of these participants said she had been told to expect a long wait.

The physiological impact of waiting

Many participants said they had gained weight during the wait period. Three participants attributed their weight gain to side effects from medication, such as for diabetes, depression or pain (Quote 8, Table 3). Reports of declining health were common and were described even when the stated wait was relatively short e.g. 2 years. A number of obesity-related conditions were reported to have developed or worsened during the wait e.g. sleep apnoea, heart conditions, arthritis, type 2 diabetes mellitus, chronic pain, high blood pressure and fatty liver (Quote 9, Table 3). One participant said she was considering removing herself from the waitlist now that she had developed diabetes, a condition she had hoped surgery would prevent. However, while not all participants' health appeared to have worsened, quality of life may still have declined (Quote 10, Table 3).

A few participants talked about their mobility deteriorating whilst waiting (Quote 11, Table 3), which for two participants appeared to be because of arthritis. One participant said she had to give up her volunteer work because of deteriorating mobility and another who had two knee replacements during the wait period, said she could not work because of her knees.

Health related behaviours during the wait

Despite common reports of a history of failed weight-loss attempts, many male and female participants said they still tried to lose weight whilst waiting (mostly through what appeared to be self-directed change to diet or physical activity) and some had done so specifically to prepare for surgery. Sometimes the changes participants reported to have made to their diets appeared inappropriate (Quote 12, Table 3), while others suggested it was difficult to eat well because healthy food was expensive. Only a few participants appeared to have experienced

sustained weight-loss during the wait (e.g. a few kilos up to 27kg) (Quote 13, Table 3), but the success did not appear to change the desire to have surgery (Quote 14, Table 3). One female participant who reported having poorly controlled diabetes and weight gain due to diabetic medication, believed that she was “*doing all the right sort of things*” (waitlisted female, wait 9 years), but felt she was not benefiting from these behaviours. Another said that he stopped walking regularly because “*nothing happened*” (waitlisted male, wait 8 years) and a male participant said he had given up trying, because despite his efforts his weight continued to increase. Even when there was a desire to engage in more physical activity, perceived barriers such as excess weight, cost, immobility, pain, poor health or fatigue could prevent this (Quote 15, Table 3).

Aside from attempts at weight-loss, some male and female participants talked about preparing for surgery by changing their diet to mimic the change required post-surgery (e.g. eating liquefied food, eating slowly, chewing food well and reducing food intake), seeking psychological support, exercising, reading related literature or “*mentally*” preparing themselves. However, one participant said that because the date of surgery was unknown preparing for surgery was futile (Quote 16, Table 3).

Support during the wait

A number of male and female participants talked positively about the support they had received from their GP during the wait period. This included monitoring their health, providing information about the surgery and attempting to get information about expected wait time, which was seldom forthcoming (Quote 17, Table 3). Except for the surgical or medical management of comorbidities, participants rarely spoke about accessing support through other health professionals or relevant programs specifically for the challenges they were facing whilst waiting. This apparent lack in seeking support may be linked to

participants' stories (mostly told by females in the waiting list focus groups) about sometimes being dissatisfied with their interaction with health professionals for reasons such as: perceiving that there was a lack of understanding of their situation; that unsuitable advice had been provided (e.g. recommending unaffordable foods); that advice received conflicted between health professionals (e.g. dietary and diabetes management related advice - Quote 18, Table 3); or that inappropriate comments were made about their weight or clinical circumstances. One participant spoke about the frustration associated with being told that she needed to lose weight whilst waiting, stating *"If I could lose weight I would have done it 40 years ago...And I wouldn't be here now"* (waitlisted female, wait 2 years).

Many men and women talked about feeling supported by significant others (partners, friends or children) during the wait period. However, support from significant others was not universally received. This was exemplified by one participant who said that her sister was *"dead against it [bariatric surgery]"*, but would also try to sabotage her efforts at weight-loss *"rather than encourage me. And it really gets me upset"* (waitlisted female, wait 7 years). Another participant said that she only told her mother and ex-husband about the prospect of surgery, because of cruel weight-related remarks made by other family members (Quote 19, Table 3). Male and female focus group participants talked about how helpful it had been sharing experiences (Quote 20, Table 3). One female in the waiting list focus group received encouragement from other participants when she suggested that a support group might benefit those waiting for surgery

Discussion

Our findings indicated that waiting for bariatric surgery was commonly associated with a range of deleterious consequences, including weight gain and deteriorating physical or psychological health. Some of the consequences of waiting appear inevitable (e.g. emotional

stress appears to be commonly associated with elective surgery waits even when wait times are relatively short (e.g. < 3 months (12)), but many deleterious effects may be improved through better communication to patients and their GPs and through peer and health professional supports. The challenge lies in determining how a public health system can provide better support for all in a resource constrained environment. This is an important area for research because the pre-surgery support experience may influence surgical outcomes (18).

To our knowledge, only two studies have investigated the effect of weight-loss interventions on patients waiting for publicly-funded bariatric surgery. In an Australian study of 82 prospective publicly-funded bariatric surgery recipients who completed a pre-hospital patient education program (involving a GP review, information session and online lifestyle behaviour modification program), 55% (n=45) maintained or lost weight and 36% (n=30) gained weight across an 18-month period. Further, at 12-month follow up post-surgery, those who completed the program had greater mean excess weight-loss (EWL) than those who did not (41.1 ± 20.3 % EWL compared with 32 ± 18.0 % ($p=0.012$)) (19). Another study of 200 participants waitlisted for publicly-funded bariatric surgery in Canada, investigated the effect of a two year individualised and interdisciplinary intervention. Thirty two percent of those in the intervention group achieved a clinically meaningful weight-loss of $\geq 5\%$ (20) compared with 17% of waitlisted patients who received no specific intervention. The proportion of those that gained $\geq 5\%$ of their body weight was comparable between the groups (11% and 13% respectively) (11). Whether the health economic benefit of such interventions outweighs the costs is unclear. Further, because these studies and others (21) indicate that non-surgical weight-loss interventions are unlikely to be effective for most in this population

group, requiring patients to lose weight for non-clinical reasons to gain eligibility for surgery (as evidenced in some policy guidelines (22)) would appear inappropriate.

We have identified that there are deficits in the communication received from those managing the waitlist about waitlist management and in the support provided during the waiting period. If these deficits were remediated it could make a difference to the quality of life of bariatric surgery candidates irrespective of weight-loss. Clear communication disseminated to both patients and their GPs about waitlist position and patient prioritisation, could lessen the emotional burden of waiting for patients. Further, many participants reported that they eagerly anticipated communication from those managing the waitlist. Health authorities could use this as an opportunity to communicate information that may improve the quality of life of those waiting e.g. include health promotion messages and information about how to access free or low cost lifestyle modification programs and relevant health services. Further, it appeared uncommon for participants to seek assistance from health professionals or through relevant programs to help them with the challenges faced whilst waiting, outside the medical management of their obesity-related conditions. Given the results of this study, many patients waiting for surgery may benefit from psychological and dietetic support and support to improve or at least maintain physical activity levels and general mobility. Whether the benefits of providing these types of supports outweighs the costs requires investigation and perceived weight-based stigma from health professionals may act as a barrier to seeking care for some patients (23).

Participants in the focus groups also talked positively about sharing their experiences, consequently the development of a support group was suggested. There was also discussion about the benefits of receiving support from family members. According to a systematic

review of 10 observational studies, social support (including support groups) provided to recipients of bariatric surgery was positively associated with weight-loss (24). The effect of social support on the experience of waiting and consequent post-surgical outcomes is yet to be determined.

Individual and health system benefits may also be gained through improvements in integrated care. Participants suggested that treatments received for conditions such as diabetes, depression or pain contributed to weight gain and that advice received from health professionals was not always aligned or appropriate. A recent systematic review and meta-analysis of 27 studies investigating the effect of integrated care programs in those with chronic illness, concluded that most studies reported a beneficial outcome, such as improved quality of life, reduced hospital admissions and readmissions and improved adherence to clinical guidelines (25).

Box 1 provides a summary of strategies that may assist people waiting for bariatric surgery informed by the results of this study and the literature where available, though they are yet to be evaluated for their effectiveness.

Limitations

Given the study design we cannot infer the prevalence of the focus group and interview themes at a population level. While data saturation was achieved by the final interview it is possible other relevant themes were not discussed. Further, there may have been recall error (e.g. change in health status over time) for some participants because of the prolonged wait time or time since being on the waitlist (Table 1 and 2). Due to the diversity in the residential addresses of participants within and between the focus groups and between the focus groups

interviews we could not stratify the analysis by residential location. Whether the experience of waiting differs between those who live in major centres or in regional or remote areas is an important area of research given the potential implications for health service planning.

Strengths

This study has provided important information for health service planners. It is one of few studies that have investigated the experience of waiting for publicly-funded bariatric surgery and the first to provide an Australian perspective. Our findings appear internationally relevant (8-11) and relevant to waits associated with many types of elective surgery (especially in resource constrained public health environments), because of commonalities in our findings compared with others. For instance, evidence of declining physical, psychological or social health has also been reported to be associated with waiting for other types of elective surgery, such as cataract, cholecystectomy, joint replacements and coronary artery bypass grafting (12, 26, 27).

Conclusion

Waiting for bariatric surgery appears to be commonly associated with weight gain and physiological or psychological health decline. The consequences of waiting for publicly-funded bariatric surgery are a product of a combination of factors including the waiting time, peer and health professional supports, and communication from health departments.

Remediating communication and support deficits may improve the experience or outcomes of waiting for patients and confer quality of life gains irrespective of weight loss.

Conflict of interest statement

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from any of the sources declared above. MH has been involved in making policy decisions and funding allocations for the provision of bariatric surgery in Tasmanian public hospitals. All other authors declare they have no competing interest.

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AP, AV, DE, DW, MH, MS and SW contributed to the study design. AV, DE, DW, KJ, and MS were involved in data collection. All authors were involved with data interpretation, writing the paper and had final approval of the submitted and published versions.

References

1. Angrisani L, Santonicola A, Iovino P, Formisano G, Buchwald H, Scopinaro N. Bariatric Surgery Worldwide 2013. *Obes Surg*. 2015;25(10):1822-32.
2. National Health and Medical Research Council. Clinical practice guidelines for the management of overweight and obesity in adults, adolescents and children in Australia. Melbourne. 2013.
3. National Institute for Health and Care Excellence. Obesity: identification, assessment and management of overweight and obesity in children, young people and adults. London. 2014.
4. Keating C, Backholer K, Gearon E, Stevenson C, Swinburn B, Moodie M, et al. Prevalence of class-I, class-II and class-III obesity in Australian adults between 1995 and 2011-12. *Obes Res Clin Pract*. 2015;9(6):553-62.
5. Christou NV, Efthimiou E. Bariatric surgery waiting times in Canada. *Canadian Journal of Surgery*. 2009;52(3):229-34.
6. Government of Tasmania - Department of Health and Human Services. Final report from the bariatric surgery careway advisory group. Hobart. 2010
7. Government of Western Australia - Department of Health. WA health bariatric surgery plan - a standardised approach to surgery for obesity. Perth. 2012.
8. Gregory DM, Temple Newhook J, Twells LK. Patients' perceptions of waiting for bariatric surgery: a qualitative study. *Int J Equity Health*. 2013;12:86.
9. Lakoff JM, Ellsmere J, Ransom T. Cause of death in patients awaiting bariatric surgery. *Can J Surg*. 2015;58(1):15-8.
10. Padwal RS, Majumdar SR, Klarenbach S, Birch DW, Karmali S, McCargar L, et al. Health status, quality of life, and satisfaction of patients awaiting multidisciplinary bariatric care. *BMC Health Serv Res*. 2012;12:139.
11. Padwal RS, Rueda-Clausen CF, Sharma AM, Agborsangaya CB, Klarenbach S, Birch DW, et al. Weight loss and outcomes in wait-listed, medically managed, and surgically treated patients enrolled in a population-based Bariatric program: prospective cohort study. *Med Care*. 2014;52(3):208-15.
12. Carr T, Teucher U, Mann J, Casson AG. Waiting for surgery from the patient perspective. *Psychol Res Behav Manag*. 2009;2:107-19.
13. Klarenbach S, Padwal RS, Wiebe N, Hazel M, Birch D, Manns B, et al. Bariatric surgery for severe obesity: a systematic review and economic evaluation. Ottawa: Canadian Agency for Drugs and Technologies in Health: Health CAFDaTi; 2010.
14. Denzin N, Lincoln Y, editors. The Sage handbook of qualitative research. Third ed. Thousand Oaks: Sage Publications; 1994.
15. Mason J. Qualitative researching. London: Sage Publications; 1996.
16. Patton M. Qualitative research and evaluation methods. Third ed. London: Sage Publications; 2002.
17. Kitzinger J. Qualitative research. Introducing focus groups. *Bmj*. 1995;311(7000):299-302.

18. Sharman M, Hensher M, Wilkinson S, Williams D, Palmer A, Venn A, et al. What are the support experiences and needs of patients who have received bariatric surgery? *Health Expectations*. 2015;n/a-n/a.
19. Brown WA, Burton PR, Shaw K, Smith B, Maffescioni S, Comitti B, et al. A Pre-Hospital Patient Education Program Improves Outcomes of Bariatric Surgery. *Obes Surg*. 2016.
20. Williamson DA, Bray GA, Ryan DH. Is 5% weight loss a satisfactory criterion to define clinically significant weight loss? *Obesity (Silver Spring)*. 2015;23(12):2319-20.
21. Fildes A, Charlton J, Rudisill C, Littlejohns P, Prevost AT, Gulliford MC. Probability of an Obese Person Attaining Normal Body Weight: Cohort Study Using Electronic Health Records. *Am J Public Health*. 2015;105(9):e54-9.
22. Sharman MJ, Hensher M, Wilkinson S, Campbell JA, Venn AJ. Review of Publicly-Funded Bariatric Surgery Policy in Australia-Lessons for More Comprehensive Policy Making. *Obes Surg*. 2016;26(4):817-24.
23. Puhl R, Heuer CA. The stigma of obesity: A review and update. *Obesity*. 2009;17(5):941-64.
24. Livhits M, Mercado C, Yermilov I, Parikh JA, Dutson E, Mehran A, et al. Is social support associated with greater weight loss after bariatric surgery?: a systematic review. *Obes Rev*. 2011;12(2):142-8.
25. Martinez-Gonzalez NA, Berchtold P, Ullman K, Busato A, Egger M. Integrated care programmes for adults with chronic conditions: a meta-review. *Int J Qual Health Care*. 2014;26(5):561-70.
26. Hodge W, Horsley T, Albani D, Baryla J, Belliveau M, Buhrmann R, et al. The consequences of waiting for cataract surgery: a systematic review. *CMAJ*. 2007;176(9):1285-90.
27. Oudhoff JP, Timmermans DR, Bijnen AB, Van der Wal G. Waiting for elective general surgery: physical, psychological and social consequences. *ANZ J Surg*. 2004;74.
28. Livhits M, Mercado C, Yermilov I, Parikh JA, Dutson E, Mehran A, et al. Preoperative predictors of weight loss following bariatric surgery: systematic review. *Obes Surg*. 2012;22(1):70-89.

Table 1 The characteristics of those waitlisted for and those who had received bariatric surgery

<i>Characteristic</i>	<i>Waitlisted</i> <i>(n=18)</i>	<i>Post-surgery</i> <i>(n=18)</i>
Age (years)		
Mean (range)	54 (39-63)	51 (23-66)
Sex		
Female n (%)	9 (50)	12 (67)
Current BMI (kg/m ²)		
Mean (range)	49 (32-65)*	43 (27-66)
Time on waitlist (years)		
Mean (range)	6 (2-12)	5 (0-10)*
Time since primary surgery (years)		
Mean (range)	-	4 (0-11)

* one missing

Key: BMI body mass index

Table 2 The characteristics of those who participated in the focus groups and those who participated in the individual interviews

<i>Characteristic</i>	<i>Focus groups</i>	<i>Interviews</i>
	<i>(n=17)</i>	<i>(n=19)</i>
Age (years)		
Mean (range)	53 (23-66)	52 (32-62)
Sex		
Female n (%)	11 (64)	9 (47)
Current BMI (kg/m ²)		
Mean (range)	42 (27-64)*	49 (32-66)
Time on waitlist (years)		
Mean (range)	5 (0-10) *	7 (4-12)
Time since primary surgery (years)		
Mean (range)	7 (2-11)	0 †

* one missing

†interviews only included participants who received publicly-funded surgery in 2015

Key: BMI body mass index

Table 3 Collation of quotes

Quote #	Quote	Characteristics
The psychological impact of waiting		
1	<i>... just waiting on the surgery, it's amazing how it crunches you – you know your self-worth. And you start to question you know am I worth having the surgery? Am I worth you know – to professionals I mustn't be worth helping.</i>	F; WL; WT 6
2	<i>...my main problem is that I just can't lose the weight and I get a bit depressed about it.</i>	M; WL; WT 8
3	<i>"It's your fault you're obese, why should we help you 'cause you don't help yourself?"</i>	F; WL; WT 2
4	<i>Just any type of contact would be great. Give you some confidence to say, "Oh okay, we're getting there."</i>	M; WL; WT 5
5	<i>Well, it's extremely frustrating waiting that long and then like I said, I got called down to the pre-op and I thought well I'm sure to be in shortly and then two years later still nothing had happened. And they were very hard to contact, like I said one girl that I was talking to got fairly abrupt and a bit rude and told me not to bother ringing again, they'd ring me. It's just all very frustrating, that's all.</i>	M; WL; WT 7
6	<i>... don't you though wonder what it takes to actually have the surgery. Like what makes a priority one over someone like us?</i>	F; WL; WT 6
7	<i>I suppose it made me more determined when I could have the surgery done to make a go of it and make it successful and not abuse it...</i>	F; PS; WT 5

The physiological impact of waiting

- 8 ...I was put on “Gabapentin” and that affected my ability to stay awake during the day. It made me very M; WL; WT 6
lethargic and as a result of that, not doing much physical exercise and whatnot, the weight that I’d lost
during my [health condition] treatment soon piled back on top of it.
- 9 So, I had a stent in my heart put in, so cardio issues, that was about ten years ago, probably 11 now. I’ve got F; WL; WT 5
type two diabetes which is basically uncontrolled. High blood pressure, fatty liver, severe arthritis, what else
was there? I think high blood pressure. I think that’s all. I’ve got depression, ... of course they’ve worsened
during that time [the waiting period].
- 10 ... my health, like I said, has been about the same for a long time. It’s not that it’s getting worse; it’s just that M; WL; WT 7
it’s hard all the time and you get a bit of sick it... it’s simple little things. I don’t do them anymore because
they’re too much trouble...
- 11 ...I can hardly walk anymore. I was walking around, I wasn’t using a stick. I had no pains in my knees, only F; WL; WT 2
in my back and now I have pains in my knees, my hip, my legs, and my feet.

Health related behaviours during the wait

- 12 ...the diabetes educator... came down to convince me that I was eating unhealthy. F; WL; WT 6
- 13 ... I feel pretty good actually. Actually, I can run now and I don’t get puffed. M; WL; WT 8
- 14 ...but I tried to lose the weight on my own and I managed to lose 27 kilos, but it was just taking too long. F; PS; WT 6
- 15 ...I was reluctant to do things like get out in the garden, or do excessive physical housework. I was doing the F; PS; WT 4
bare minimum that I needed to do because it just made me feel tired all the time.
- 16 There’s no way you want to drink soup and smoothies for six months or longer. Which is why I’m not going M; WL; WT 5

down that type of route until I get confirmation.... It's not worth it.

Support during the wait

- 17 *And my doctor rang them the other day while I was there and they wouldn't tell him anything. It's not good.* M; WL; WT 7
- 18 *... no matter how many people you see, they all have a different opinion. Their opinion is correct and you're left to juggle what you can afford and what you can do to please everyone so you're not ... feeling bad when you go and say, "Well look I couldn't do that or I couldn't do that this week," but you know – it puts you in a really awkward position. It makes you feel very uncomfortable. And so if the health professionals could just get it right, then maybe we could have a chance of doing something positive if they were all on the same page.* F; WL; WT 6
- 19 *"Oh aren't you uncomfortable like that? Don't you hate being fat?"* F; PS; WT 2
- 20 *...but the thing is it's been good to come and talk to someone and say, "God I feel like crap that I've been waiting," or talking to somebody else that feels the same you know...I'm not the only one going through this, there's others out there.* F; WL; WT 7

Key: F female; M male; PS post-surgery; WL wait list; WT wait time (years)

Box 1: Recommendations that may improve the experience and outcomes of waiting

- At least annually provide patients and their GPs with information about waitlist position, expected wait time, explain delays and patient prioritisation.
- Encourage ‘active’ waiting by regularly providing patients with information on accessible low cost or free lifestyle modification programs and support services such as dietetics, counselling and support groups (face to face and on-line).
- Frequently promote to patients the importance of healthy lifestyle habits, and the potential positive health impact of improved diet and mobility or physical activity levels independent of weight-loss.
- Promote to patients the potential benefits of social support (e.g. through family and friends and online or face to face support groups) during the wait period (28).
- Where possible improve integration of care to ensure alignment and appropriateness of treatment goals for patients (25).
- Ensure training for health professionals in obesity management includes information on the impact, identification and remediation of weight based stigma or discrimination (23).

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