'The rollercoaster of follow-up care' after bariatric surgery

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DOI:
10.1111/obr.12764

Summary

Benefits of bariatric surgery for obesity related co-morbidities are well established. However, in the longer term patients can become vulnerable to procedure specific problems, experience weight regain, and continue to need monitoring and management of co-morbidities. Effective longer term follow-up is vital due to these complex needs post-surgery. Current guidance recommends annual long term follow-up after bariatric surgery. However, attendance can be low and failure to attend is associated with poorer outcomes. Understanding patients' experiences and needs is central to the delivery of effective care. This rapid review has synthesised the current qualitative literature on patient experiences of healthcare professional (HCP) led follow-up from 12 months after bariatric surgery. A recurring theme was the need for more and extended follow-up care, particularly psychological support. Enablers to attending follow-up care were patient self-efficacy as well as HCP factors such as a non-judgemental attitude, knowledge and continuity of care. Barriers included unrealistic patient expectations and perceived lack of HCP expertise. Some preferences were expressed including patient initiated access to HCPs and more information pre-operatively to prepare for potential post-surgery issues. Insights gained from this work will help identify areas for improvement to care in order to optimise longer term outcomes.

Introduction

Bariatric surgery is recognised as the most effective treatment for severe and complex obesity (defined as those with a BMI≥40kg/m^2 or 35-40kg/m^2 with obesity related co-morbidities) (1). Globally, the annual rate of bariatric surgery procedures is increasing resulting in a growing cohort of patients living with a history of bariatric surgery (2, 3). In the USA over 1 million patients had bariatric surgery between 2011 and 2016 (4). Between 2001 and 2015 approximately 56,000 patients had bariatric surgery in the UK. Rates of surgery vary in Europe with France having the highest rate of around 47,000 (2) while in the UK around 6000 primary procedures are performed annually (5).

Patients who undergo bariatric surgery are medically complex with on average 51% of men and 39% of women having four or more co-morbidities pre-surgery (5). Benefits of bariatric surgery are well established, such as remission of type II diabetes, improvements in hypertension, obstructive sleep apnoea, hyperlipidaemia and functional ability, as well as, reduction in cardiovascular disease, some cancers and mortality (5-8). Weight loss in the first two years after surgery can be significant (6). However, from 18-24 months regain weight can occur (9). Weight regain trajectories vary by patient and procedure; with reports that 73% of gastric bypass patients regain 15% of initial weight loss (10) while 3.5% of gastric band patients regain 25% (11). Following bariatric surgery patients become vulnerable to procedure specific problems, which can have longer term consequences. These include a risk of nutritional deficiencies such as protein malnutrition (12-14), micronutrient or vitamin deficiencies (15-18), as well as, eating behaviour problems and dumping syndrome (a condition where the intake of high sugar content foods results in symptoms such as sweating, flushing, diarrhoea, abdominal pain and dizziness) (12, 19-21). Bariatric surgery has a profound effect on patients' pre-existing co-morbidities and the management of these conditions also needs to be modified and monitored following surgery (3).

This range of both pre-existing and post-surgery problems that can be experienced by patients highlights the complexity of their care needs and the necessity for good quality longer term follow-up care. The American Association of Clinical Endocrinologists/The Obesity Society/American Association of Metabolic and Bariatric Surgery guidelines recommend routine metabolic and nutritional monitoring for all patients who have had bariatric surgery as well as a review of weight, eating behaviours and physical activity (16, 18). In the UK, the National Institute for Health and Care Excellence (NICE) recommends that bariatric surgery patients should stay under the care of the specialist surgical unit for the first two years post-surgery and then be discharged to primary care under a shared care model with annual reviews (1). Recently, the European Association for the Study of Obesity (EASO) published detailed guidance for non-specialists (3) that also highlighted the need for longer term follow-up for patients following bariatric surgery. EASO recommended that longer term follow-up needs should be transferred to primary care physicians and other non-surgical health care professionals (HCPs) when clinically appropriate (3), concurring with NICE guidance (1).

However, attendance for follow-up care can be low with attrition rates varying between 3% and 63% depending on the procedure and follow-up programme (22-25) and failure to attend follow-up is associated with poorer outcomes (26-29). An understanding of patients' experiences and needs is central to the development and delivery of effective longer term follow-up care. Qualitative research can provide an in-depth description and understanding of patients' experience of disease and treatment. There have been relatively few studies using qualitative methods focusing specifically on patients' experience of longer term follow-up care after bariatric surgery. A qualitative synthesis was recently published by Coulman *et al.*, which focused on patients' experiences of living with the outcomes of bariatric surgery, but did not explore follow-up care experiences (30). As far as the authors are aware, there have been no previous qualitative syntheses of patient experiences of HCP led follow-up after bariatric surgery. However, there have been several qualitative studies that have explored the lived experience of bariatric surgery (31, 32) and within these studies there is the

potential to extract data on experiences of longer term follow-up care post-surgery. This qualitative synthesis and rapid review therefore aims to explore and synthesise the current primary literature on patient experiences of HCP led follow-up from at least 12 months after bariatric surgery. We hope to gain an in-depth understanding of patients' experiences of long-term follow-up care after bariatric surgery, including: enablers and barriers to attendance; experiences of the different HCPs providing follow-up care; experiences of longer term complications as well as expressed needs and preferences for follow-up care. The insights gained from this review are likely to help identify areas for improvement to care pathways in order to optimise longer term outcomes following bariatric surgery from both a patient and clinical perspective as well as ensuring patient safety.

Methods

The protocol for this review is registered on PROSPERO (registration number: CRD42017060538) and has been reported with reference, where appropriate for a rapid review, to the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) framework (33). We have undertaken a rapid review of the literature, within a limited timeframe, with the needs of health policy decision makers in mind (34). The only difference in our review compared to a traditional systematic review is that we have narrowed the scope of the search by searching a more limited number of databases without further search supplementation. Data extraction, critical appraisal, and qualitative synthesis are in line with established systematic review and qualitative synthesis methods. The thematic synthesis approach proposed by Thomas and Harden (35) was followed to facilitate the synthesis of the qualitative data within the current review. Thematic synthesis is a structured approach that involves inductive and interactive analysis of data to facilitate the development of codes, descriptive and analytic themes whilst maintaining a transparent and auditable link between the original data and the synthesis findings (35). The review team included expertise in qualitative evidence synthesis (LLJ), adult obesity, post bariatric surgery care and general practice (CAH, HMP).

Identification of primary research studies

Search Strategy

The following databases were searched: MEDLINE (health sciences manuscripts); EMBASE (health sciences manuscripts); and CINAHL (nursing manuscripts) from inception to March 2017. The search strategy was developed to identify qualitative studies focussing on adult bariatric surgery patients' behaviours, experiences, and perceptions around longer term follow-up care. Search terms were modified as appropriate for each databases and an example search strategy is reported in the supplementary information for this paper.

Inclusion criteria

(1) Studies must have used qualitative data collection and analytic methods. Mixed-methods studies were included where qualitative data were coherent with a clearly reported qualitative approach. (2) Studies with adult participants (>/=18 years) who had had bariatric surgery for weight loss, privately or publicly funded. (3) Bariatric surgery procedures for weight loss including: gastric bypass, Roux-en-Y gastric bypass, gastric band, duodenal switch, and sleeve gastrectomy. (4) In current international clinical practice there is variability in timing of discharge from specialist care, but it is rarely prior to 12 months post-surgery. Therefore, we included studies with patients who were at least 12 months post-surgery to avoid those in the initial intensive follow-up period (3). For studies where a range of dates post-surgery were reported they were included if the average post-surgery time was 12 months or longer. (5) Studies that included a focus on follow-up appointments or contacts with HCPs (including for example: clinicians, nurses, psychologists, physiotherapists, dietitians) that were face to face, electronic or via telephone and in either primary or secondary cares settings. (6) Studies with a focus on support groups that were initiated or facilitated by a HCP. (7) Outcomes of interest included the feelings, behaviours, preferences, thoughts, and opinions of the participants, gathered from them directly.

Exclusion criteria

(1) Studies not available in English language. (2) Non empirical studies (e.g. commentaries, letters, editorials, reviews, books, theses, conference abstracts, case reports and opinion pieces). (3) Studies where the participants were more than 12 months post-surgery but the data presented in the paper were pre-surgery or within the first 12 months post-surgery. (4) Studies where the time since surgery was not stated, unclear, or the data for those more than 12 months post-surgery could not be disaggregated from those with more recent surgery.

Study screening, data extraction and quality appraisal

Following removal of duplicates, all titles and abstracts of potentially relevant articles were screened by a single reviewer (HMP), with uncertainties resolved via discussion with a second reviewer (LLJ/CAH). All publications possibly relevant were obtained in full if available, and reviewed for inclusion/exclusion by two of three independent reviewers (HMP, CAH and/ or LLJ) (Figure 1). Study characteristics from each article were extracted by one author (HMP/CAH) using a pre-designed proforma and checked by a second author (LLJ) (Table 1). For each article, all text and participant quotations from the 'Results/Findings' and the 'Discussion' were extracted by one of two reviewers (HMP/CAH) and imported into NVivo V11 (36) for data synthesis by a separate author (LLJ). As this was a rapid review, if an article was considered relevant, but the data insufficient or not available in the required format the article was excluded (Table S1, supplementary information). All included manuscripts were also assessed for methodological quality using the CASP Qualitative Research Checklist (37) and for conceptual richness (38) by two independent reviewers (HMP/CAH) with discrepancies resolved until consensus with a third (LLJ). As a result of the ongoing debate (39, 40) regarding methods of appraising the quality of articles for inclusion in qualitative systematic review all studies were included in the synthesis if the contributed conceptually regardless of the assessment of their methodological quality (Table S2, supplementary information).

Data Synthesis

Primary participant quotes and authors' interpretations of the data reported in the results/findings or discussion sections of included papers were synthesised. Equal weighting was given to primary quotes and author interpretations. Within each paper, only the sections of the results/findings and discussion that were relevant to our qualitative synthesis and that related to the paper's primary data were coded. Initially, two articles (41, 42) were identified as index papers (as they were well reported and conceptually rich) and were independently coded line by line by all three authors (HMP, CAH, LLJ). This was followed by in-depth discussion and consensus to develop a working code book. This process was repeated with a further eight articles (31, 32, 43-48) by two authors (HMP, CAH) to iteratively develop and refine the working codebook. The remaining articles were then split between two authors (HMP, CAH) for coding and the final code book agreed via consensus discussion (HMP, CAH, LLJ). Coding was grouped into descriptive categories which were further developed into descriptive themes, and finally developed into analytical themes. The overarching analytical themes and related subthemes are presented in Figure 2. All members of the multidisciplinary team were involved in each stage of the thematic synthesis.

Results

Summary of included papers

Twenty articles were included and the characteristics of these are described in Table 1. Seven studies collected data in the USA, three in the UK, three in Australia or New Zealand, one in Canada and six in mainland Europe (Norway, Sweden and the Netherlands). The majority of the studies used a qualitative approach, with two reporting the use of mixed-methods (49, 50). Data were reported for 887 patients across the 20 studies.

Overall, patients described a complex mixture of physical and psychological issues experienced over time following bariatric surgery and expressed their need for support from HCPs to manage these.

This was particularly desired at the transition from specialist to more generalist care which tended to occur 2-3 years post-surgery and coincided with the reduction in the biological changes driving weight loss, and start of weight regain (51, 52). Patients reported a fear of losing control of their eating and weight in the subsequent years: *"It's a rollercoaster… just shot off with it, there wasn't much control. You know it was all up and down when you went for the ride you were not in control of it at all. It's about that lack of control… has been all along… I mean it controlled what I ate but I wasn't in control of it…That's what frightens me..."* (46).

Core themes and their inter-relationships

Core themes and their inter-relationships are represented in the model shown in Figure 2 with additional quotes shown in Table 2. Author interpretations are shown in normal font and patient quotes in *italics*. Our interpretation is that a core component to the experience of post bariatric surgery longer term follow-up care was ***access***ing HCPs and their support during the post bariatric surgery care journey. There were particular time points during the post-surgery journey ***when*** HCP support was particularly needed and desired. Patients also reported experiences and views on the ***type*** of access they had had to HCPs, ***what*** type of support was required, as well as, ***who*** should be providing the support.

Access to HCP support in turn had an influence on whether the ***quality*** of experiences with HCPs were viewed as more positive or negative. This was reported as having an effect on the patient-HCP relationship and in some cases it influenced the patients' attendance at future HCP appointments. Patients' experiences and satisfaction with post bariatric surgery care were also influenced by factors relating to either themselves or the HCP. Examples of ***patient factors*** that particularly impacted on interactions with HCPs were self-efficacy and expectations of their surgery, while attitude towards the patient and continuity of care were ***HCP factors*** that were reported to be of significance to the patients.

ACCESS

Problems frequently arose between routine follow-up appointments and timely access to care was reported as important (47). This included the ability to telephone the HCP for advice on an ad hoc basis: *"…all I had to do was ring her [nurse]"* (47) and for HCPs to help patients to "troubleshoot" (53) physiological problems post-surgery.

Routine appointments and monitoring motivated some people to attend (44), but others reported difficultly attending due to location (52), time of appointment (52), work or family commitments (52) or expense (42). Some had an expectation that the HCPs would initiate more contact (44). In contrast, others expressed a preference to be able to contact HCPs themselves only when they had concerns rather than attending regular appointments (44).

Many patients recognised their need for help from psychologists (41-44, 54), valued it (53), and desired greater access to psychological support (31, 41-48, 51-55). Access to support groups was valued (43, 49), but others perceived them as offering care mainly for those in the immediate post-op period with longer term patients feeling *"alienated by the topics and discussions"* (52). In addition, although keen to attend support groups, patients reported problems accessing them, leading to feelings of frustration and anger (48).

Access to additional information via remote means such as Internet based information, or text messages was considered acceptable (41). Several studies reported patients expressing a need for more information prior to their surgery to better prepare them for post-surgery experiences (42, 49, 51).

Access to plastic surgery for excess skin was a significant problem for a number of patients (32, 42, 48, 51, 56, 57). They described difficulty accessing plastic surgery for excess skin as *''frustrating''*, *''unacceptable''* and *''mentally stressful"* (56). Participants felt they had to *"beg and implore"* (56) to be granted surgery.

QUALITY

Once HCP support had been accessed, the quality of the interaction was perceived by patients as either a more positive or a negative experience. There were commonalities in the experiences that were viewed as negative with patients expressing frustration with HCPs either due to their perceived lack of expertise in obesity or due to their attitudes towards the patient themselves. A particular frustration was when patients felt that their concerns were dismissed as being due to mental rather than physical health: *"…their explanations made me really annoyed and frustrated. It cannot be reduced to mental problems…"* (57). Patients experiencing weight regain also found the lack of understanding of the psychological aspects of controlling their weight by doctors frustrating: "*Most doctors, even now, won't recognise that over-eating and issues linked to obesity are a mental health problem. It can be emotional…but they don't acknowledge it…to lose weight, you need to look at the bigger picture. What happens with the body, what happens with the mind*" (31).

This theme was strongly aligned with the ***access*** theme with patients' perceptions of the quality of an interaction with a HCP often associated with simply being able to access that HCP.

WHEN

This theme appeared to particularly impact on the ***quality*** of the interaction and encompassed the timing of when a HCP was seen during the post-surgery journey as well as the duration and frequency of contacts. The desire for more follow-up care was an overriding message from the patients in the studies. The first 18-24 months following surgery were described as a *"honeymoon"* (41, 48, 51) *" 'with the weight just dropping off' and 'feeling ten foot tall and bullet proof'*. This early stage was further described as *'exciting'* and feeling like you are '*on a bit of a high'* as *'no matter what you do, the weight keeps falling off'*. Once the *'honeymoon*' was over, participants described *'coming down to reality'* when the weight loss just stopped and *'everything went to custard' "*(41).

Eighteen to 24 months after surgery was also the time at which patients were discharged from specialist care. Discharge often coincided with a time when weight loss plateaued and patients began to experience difficulties adhering to lifestyle and dietary advice. Patients felt that they needed extra support and instead found that they were being discharged from specialist service support (41, 46). Patients experiencing weight regain reported that the tailing off of the provision of regular follow-up appointments after the first year led to feelings of *"abandonment and disempowerment"* and that the transition from specialist care provoked anxiety (46). Many patients were dissatisfied that regular care stopped at this transition time (41, 46, 48, 51). In general, the duration of the follow-up programme offered was not reported (Table 1), but where reported patients were offered follow-up care for 1 year (51), 1.5 years (41) and 5 years (48).

Support and help with emotional eating was desired, often by those experiencing weight regain (41, 46, 48). Patients were aware of their emotional eating behaviour, but expressed a need for help and support to change their behaviour (46).

In addition, this was also a time when some patients reported experiencing complications such as dumping syndrome, highlighting this time point as a critical period in the patients' post-surgery journeys and linking to the ***access*** theme reported previously (58). However, there were other voices expressing the opinion that less support was needed after the early years post-surgery (44, 47). Aligned with the more general narratives around ***access*** to HCPs, patients valued regular contact due to the impact it had on their motivation and support it provided, while others appreciated being able to make patient initiated contacts in addition to regular HCP appointments and the reassurance it provided (44). The frequency of appointments was dictated by the specialists, or occurrence of medical problems, rather than discussion with patient about their perceived needs (44).

Significant life events were reported as additional time points when patients were vulnerable to weight gain and needed additional support: *"After 2 years I started to regain weight. And then I got a*

divorce. I'm the kind of person who eats in response to emotions…so I gained weight. At first just a little bit, about 5 kilos, and then it stabilized. Then I moved in with my new boyfriend and things got a bit turbulent. I put on more weight during the following summer and found I'd regained half of what I'd lost." (48)

WHO

HCPs most frequently discussed in the studies were bariatric nurses and psychologists but views were also reported on dietitians, general practitioners (GPs) and to a lesser extent bariatric surgeons.

Bariatric nurses

Bariatric nurses were viewed as *"absolutely essential"* (47) and the *"top medical person"* (47). They provided *"just reassurance"* (47) as well as being the first choice of contact with concerns or problems (47). They were perceived as being *"there for you"*, *"on your side"* and *"taking an interest"* (47). Patients' reported nurses as having the knowledge to understand their experiences of having bariatric surgery (41). Both regular routine follow-up and the ability to initiate contact with the nurse themselves when problems arose were viewed positively as highlighted above in ***access***. Patients also liked the continuity of seeing the same nurse from the pre-operative through to the post-operative period, allowing a close relationship to develop between the nurse and patient (linking with ***HCP factors*** below): *"I spent hours with the nurse. She prepares you for the surgery, checks with you after the surgery. I still see her, nearly 18 months down the line. I have a really strong link with her"* (47). In contrast, others felt that as time progressed and their confidence grew that they did not need such close contact with bariatric nurses as they had initially (47).

Negative factors relating to nurse follow-up included the desire for more HCP contacts and more information in the pre-operative period so patients would be better prepared for issues they may experience post-operatively (51).

Bariatric surgeons

Some patients expressed satisfaction with bariatric surgeon follow-up and trust in their expertise (44, 53). In contrast, others reported that bariatric surgeons did not get *"involved"* or know *"about fat people's issues"* (47).

Psychologist

Although psychological support was highly valued and desired by patients, it was felt that there was not enough psychological input post-operatively and this was a significant missing component of their care (as highlighted above in ***when***). There was an expressed need for support that continued for longer into the post-operative period (44, 48): *"There's a serious gap in the health care system. What's the use of being monitored, followed up for 5 years, measured, and weighed, if you're not encouraged to talk about where you are in your life? There's nothing like that. Before the surgery we all take the preparatory course where you have these kinds of topics that are discussed in groups" (48).*

Psychological support was also desired to help manage the significant physical transition experienced when losing weight after bariatric surgery (54). For others, the need for support was related to psychological issues that had been present before surgery, but continued to persist after surgery such as emotional or disordered eating: *"Yes, I feel scared,…. it just feels like the whole operation was a physical cure for a mental problem and of course it doesn't actually effect a cure. It gives you a handup but it, you know, doesn't stop…."* (46).

Addiction problems can be an issue for patients following bariatric surgery with the development of alcohol or drug dependence (59). Where this issue was discussed in the studies, patients reported that they were not warned of the risk, felt unprepared (49, 54) and that psychological input was

needed around addiction problems after surgery (43): "*I don't know if there is an exact link [with alcohol]. Doctors should mention the possible link. If I was told there was a possible connection, I would have watched my drinking. They never said how bad it was."* (54).

Dietitians

Positive experiences were reported with dietitian support to maintain behavioural changes and achieve weight loss (42). In contrast, others expressed concerns about the lack of consistency in dietitian staff and frustration with being given advice on food purchases that were unaffordable (41, 42). Patients also expressed frustration at being given general dietary advice that was not specific to post bariatric surgery and a need for access to a dietitian with specialist bariatric surgery knowledge (42). A particular issue was access to dietitian advice or appointments after surgery in comparison to pre-surgery access*: "I mean I did see a dietitian for a short period before I had the surgery, but I had no advice on what or how to eat post-operatively and I really missed that. I can see it would have been most beneficial to have had that support."* (42)

General practitioners

GPs were perceived to be *"professional and caring"* (44) but the duration and structure of appointments were an issue with patients feeling they were *"too short and routinised"* (44). There were positive experiences of GPs' involvement in post bariatric surgery follow-up care, for example their role as a patient advocate in accessing revisional surgery: *"…If it weren't for my general practitioner, I would never have been re-operated. He has talked to surgeons numerous times. He insisted that something was wrong. He knew I was not functioning…"* (57). Others valued the role their GP had in their care due to their *"extended"* and regular relationship with the patient (42). This included their role as a single point of contact, regular monitoring, knowledge of the patient, healthy lifestyle behaviour advice and knowledge about bariatric surgery (42). However, some reported that GPs had poor levels of knowledge, negative attitudes about bariatric surgery, as well as a lack of

understanding of the difficulties patients experienced with their relationship with food or making changes to their lifestyles (44, 47). Others reported that they felt that their relationship with their GP was not strong enough to raise their difficulties during appointments (44).

Patients also believed that GPs expected patients to comply with recommendations and did not understand reasons for non-compliance or encourage discussions to find solutions to the patients' problems: "… Most patients believed that they would be disappointing their GP if they did not meet the program's … expectations. They explained that overcoming the intense negative feelings associated with a sense of failure to meet the program's expectations was enormously difficult; cancelling or postponing their appointment was an easier alternative." (44)

HEALTHCARE PROFESSIONAL FACTORS

Certain HCP factors influenced patient satisfaction, as well as attendance at follow-up care. These factors could influence the patients' perception of the ***quality*** and utility of the interaction. The perceived attitude of the HCP could impact either positively or negatively on the rapport between the patient and HCP. Accounts of negative experiences included feelings of frustration with HCPs (57, 58). Negative experiences were reported to lead to a loss of faith in the HCP, feeling that they were not being listening to and that the follow-up was more for the HCP's benefit than the patients (48). In particular, patients recounted feeling reluctant to share their problems with HCPs when struggling to adhere to advice and some reported that this led to non-attendance at follow-up care appointments (44).

"The 5-year follow-up at the hospital was not a nice experience. … When I finally got into his office, he was more focused on writing then talking with me. He kept asking the same questions over and over again. He weighed me and was not impressed. That year I had regained a lot of weight. I tried to talk to him about it and told him I was eating a small piece of chocolate every day. He responded as if this was the worst thing he ever heard, as if nobody else ever did that. After that, he lost complete interest

in me. He didn't suggest or offer any advice on programs to help get me back on track. Nothing like that, because I was the stupid one eating chocolate every day, so I only had myself to blame. I would have asked him for help, but I didn't have any faith in him by that point. I got the feeling the follow-up was really more for their sake than for mine." (48)

In contrast, positive experiences with the HCPs acting as *"cheerleaders"* praising progress, giving encouragement and providing support were highly valued (53). A non-judgemental attitude was an attribute that was appreciated and felt to be as important as the HCP's level of knowledge (47). HCPs who acted as advocates for the patient and provided emotional support were highly appreciated (47) as was the impression that the HCP was "invested in them" (53).

Some patients emphasised the importance of the contact being individualised and patient centred as this aided motivation (41). Related to this, both the continuity of the relationship and the HCP's awareness of the individual patient were both viewed as positive HCP factors (47). The importance of regular attendance to maintain motivation and to improve the likelihood of success for their surgery was acknowledged by some patients (44).

WHAT

This theme was closely aligned with the theme of ***who*** the patient saw for follow-up care.

Psychological

Psychological support and need for therapy was frequently cited in the studies (31, 41-49, 51-55). Patients frequently suggested that more access to psychology appointments should be available, and over a longer period of time (42, 46). Issues identified included poor body image or body dysmorphia, depression, and disordered or emotional eating (31, 41, 42, 46, 48, 50, 51, 54, 55). There was an ongoing struggle with the psychological issues associated with obesity. After the

surgeons *"fix the physical side of it"*, the patient must then *"fix the inside"* (41) aligned with ***quality*** reported above.

Medical/surgical

Those with existing medical problems attended medical follow-up appointments willingly: *"I had type 2 diabetes on insulin…Now I don't have any diabetes at all. It has made a huge difference to my life…so I am pretty good about coming"* (44). New surgery specific complications such as hypoglycaemia, or dumping syndrome also triggered appointments (58). Excess skin after weight loss was an additional problem for some and it was perceived as unsightly with patients reporting that it led to the avoidance of situations similar to those they previously avoided due to their obesity, such as swimming or undressing in the presence of their partner, and affected their self-esteem (42, 51). In addition, they once again needed a healthcare intervention that was difficult to obtain, namely, plastic surgery (51). Other people viewed appointments as only being for medical issues, and therefore if they had no current medical issues, they saw no reason to attend (44).

Dietetic

A few patients discussed the benefits of receiving professional dietetic input which provided important reinforcement or new knowledge or facilitated behaviour change post-surgery (42, 55)*: "Once she [the dietitian] seen me I started to lose weight, and she also gave me some advice on how to manage the eating with the lap-band"* (42). Others thought that they had sufficient knowledge, and did not need the dietitian's factual advice, although they might need help implementing behaviour change: *"We know what we have to do, we just can't do it. I had every dietician referral ever, and it's the same thing, eat all the green stuff; we all know it, we just don't do it"* (44).

Behavioural

The study by Dikareva *et al.* (50) was the only study to specifically focus on physical activity post bariatric surgery and patients reported only cursory advice to exercise from HCPs with no specific

strategies around physical activity. They did receive support from personal trainers and the wider bariatric team (50). Several studies discussed difficulties patients reported in maintaining behavioural changes following bariatric surgery and the factors that could influence their chances of success (43, 44, 52, 54, 55). Engstrom *et al.* (51) noted the importance of patients believing in their ability to achieve goals in relation to surgery. This required supportive education on realistic expectations including the likelihood and causes of weight regain to aid self-efficacy and self-management of weight regain (51). Individuals who reported regularly attending follow-up meetings and exercise classes were more likely to adopt a healthy lifestyle and had greater initial weight loss (43, 44). Many patients had a long history of unsuccessful dieting and noted that the struggle with making behavioural changes persists beyond the surgical procedure and requires ongoing support into the post bariatric period (55). As highlighted in the section on psychologists, patients did not recall being warned about the risks of alcohol and substance misuse prior to surgery and for some this became a post-surgery problem (54).

TYPE

Individual

As previously discussed in the ***HCP factors*** theme, patients valued individualised, patient centred specialist care with active patient participation (41, 44, 47). The quality of individual appointments varied, with reported experiences varying from good (46) to disappointing (48): *"I need the accountability, I need to know that actually someone's going to say I need to see you, we need to get you on the scales, which is why coming back here (outpatient clinic) is really good..."* (46). The opportunity of long term continuity of care with either a specialist HCP or GP allowed advice to be tailored to the individual patient (41, 44, 47).

Group

Outpatient support groups were frequently mentioned as appreciated (32, 42-44, 46, 47, 51-54), but there was little detailed information on the composition and content of the groups. Peer support was consistently reported as valuable: *"The support groups are really important because then you realize you're not alone"* (43), although a few patients reported negative experiences in the group setting, feeling vulnerable and judged by their peers (46). Support groups were sometimes perceived as being geared more to those who had recently had surgery *"newbies"* (49) rather than longer term post-operative patients *"vets"* (49) with the needs of each group of patients differing (43, 52). In particular, patients experiencing weight regain differed from those in the *"honeymoon"* period (41, 48, 51). There was a natural attrition in attendance over time, which might reflect the information content or composition of the group (41, 47). The groups were often led by a bariatric nurse, and geared towards provision of information, with less discussion of psychological issues (32).

Face to face vs remote

Face to face consultations were highlighted as being important (41, 44), but remote care was acceptable (41). Telephone consultations with the bariatric nurses were supportive, and the ability to phone the nurse or specialist unit to discuss problems as they arose was useful (47, 53). Patients also embraced the idea of additional support, including non-traditional methods: *"I think you need some other sort of support and I don't know whether it's group support or it might be motivational texts. "Are you eating too much?" "Are you still drinking your water?" I don't think coming here is the answer"* (41). Other types of follow-up that were suggested by patients included internet based support (41).

PATIENT FACTORS

Expectations

The patients' expectations of weight loss after bariatric surgery and achievement of weight maintenance was described as being significant to patients' wellbeing (46, 48). Weight regain is likely

after bariatric surgery, but many patients were unaware or unprepared for this (46, 49). Geraci *et al.* discussed that weight regain could have a large effect on the *"*patients' self-concept*"* (49), and lead to psychological problems (49). As a consequence patients reported sometimes avoiding follow-up clinics (44, 46, 49). Problems also occurred when there was a mismatch between the expectations of the patient and the HCP (such as for weight loss or eating behaviour). This was reported as de-motivating, and discouraged attendance (41, 44). Some patients were surprised at the degree of planning and organisation required to maintain a healthy diet and weight: *"From the minute I wake up until I go to bed, I think about nothing but food. And I really didn't expect that part of surgery. I thought it'd be like, 'Oh I wouldn't think of food at all, I would never eat'"* (45).

Patients who did not attend follow-up regularly described a range of unmet expectations (41), and in particular described emotional difficulties, and feared disappointing the HCP if they were unable to meet dietary or physical activity targets (44). They did not think that the HCP understood their problems (44).

Capacity to understand

Patients' baseline pre-surgical nutritional literacy (42) and knowledge about bariatric surgery affected their post-operative information and support needs (42, 54). Patients' knowledge about longer term weight regain, and possible nutritional deficiencies was often incomplete (42) and was closely aligned with patients' ***expectations*** as discussed above. A thirst for more knowledge on medical, dietary and psychological issues was evident in several studies (42, 46, 49, 55).

Self-efficacy

Prior to bariatric surgery patients had the goal to take back control of their weight, and improve their quality of life (43). However, around the 18 months point there was a tendency to move from confidence to fear of gaining weight (49, 51, 58). Those who maintained control of eating, and weight reported gaining a *"new normality"* (51). A feeling of control was also reported to improve

self-esteem, social life and physical and mental wellbeing. Control was a recurring theme (32, 43-46, 55). Developing self-efficacy, confidence that they could actively plan strategies to manage difficult situations, rather than just relying on willpower or self-control was reported as important. Support from HCPs had the potential to play an important role in helping patients develop self-efficacy (41).

Taking responsibility, both for dietary changes and attendance at follow-up was a common theme. This involved self-monitoring, planning, and seeking help when required from a variety of sources*: "It's her job [GP] to give me the advice and I accept that it's her job to do it, and it is useful to be reminded, but it's not changing my behaviour. I regard (that) the success or the failure of the whole process is largely up to me rather than up to them. I simply have to exhibit more willpower… It is my responsibility, nobody else's."* (44)

In contrast, some of those who had regained weight viewed themselves in a negative way and blamed themselves for being weak or lazy (48). Other patients took a more passive role, exhibiting helplessness and blaming others when they regained weight (44, 46). Poor self-image, shame and self-blame were reported as negatively influencing attendance, as did fear of being judged by the HCP. These factors were often described as present at the time of weight regain, were reported to lead to cancelling or postponing appointments and acted as a barrier to accessing help in a timely manner: *"My shame would not allow me to go back. You don't want to own up to it, you don't want to face up to it. The emotional anguish is so great for you…if you are feeling miserable about it, you won't go."* (44)

Wider health issues

One of the main motivators for surgery was to improve health and for women, in particular infertility was an important driver: "Two out of four women who had been unable to become pregnant before surgery had now given birth to a child and for them that was the biggest benefit of surgery. They described their joy, not only of becoming pregnant, but also about how they could be active in their

parenting role" (51). Unhealthy behaviours such as emotional eating could persist post-operatively, and remain a problem and confounder to weight loss (48, 55). Emotional difficulties were a common reason for not attending follow-up appointments (44). Adverse health events such as an accident that influenced physical activity were perceived to impact on weight loss (55).

Finance

For some patients the financial burden of attending follow-up appointments could be an issue as could the costs of buying healthy food or using exercise facilities and were barriers to following follow-up advice (41, 42)*: "She [dietitian] wanted me to eat all these fancy things and I thought, "I can't afford half this stuff"* (42).

Discussion

As far as the authors are aware, this is the first qualitative synthesis of patients' experiences of longer term follow-up post bariatric surgery and has highlighted the complexity of these patients' needs. A recurring theme was the need for the period of access to a specialist's support and follow-up care to be extended and, in particular, the provision of more psychological support to help with behaviour change, weight maintenance and self-efficacy.

Several enablers to attending longer term follow-up care were identified, including patient factors such as self-efficacy as well as HCP factors such as specialist expertise and non-judgemental attitude, allowing the delivery of appropriate and individualised advice. Barriers to attendance included unrealistic patient expectations, low self-efficacy, as well as a perceived lack of HCP expertise. In addition, feeling that concerns were dismissed also had a negative impact on patient interactions with HCPs.

Those who had begun to find it difficult to maintain weight loss and behavioural changes expressed feelings of shame, similarly to those expressed in other patient groups experiencing behavioural relapse, for example, in alcohol misuse (60). These feelings of shame could lead to non-attendance

at follow-up, which could then extend to appointments for unrelated medical problems. So potentially when patients needed more support they felt unable to ask for help and opportunities to find solutions to their problems may have been lost. Some preferences for follow-up care emerged, including continuity of care, the ability for patient initiated access to an appropriate HCP, an increased psychological component and specific support to address weight regain. However, there were some dissenting voices reporting that they did not feel that they needed any additional care.

There was a clear desire for more and improved information pre-operatively to prepare for potential post-surgery issues. This may lead to more realistic expectations of surgery, which may, in turn, increase the likelihood of patients seeking help to develop strategies to manage their weight and self-efficacy in the longer term.

There are parallels between our findings and those identified in studies on other long term post-surgical follow-up such as cancer survivorship, for example a need for more information, difficulties at care transition points and living with a "new normal" (61, 62). However, bariatric surgery patients need to be more actively engaged in maintaining behavioural changes and less passive recipients of medical advice compared with cancer survivors. Our findings also resonate with those from a recent retrospective study of support group needs for patients who have been discharged from specialist bariatric surgery follow-up care (63). This revealed an unmet need for a post-operative support group that extended well beyond the immediate post-operative period of specialist follow-up and suggested that support with weight loss maintenance was an important part of post-operative care (63). To our knowledge there has only been one previous qualitative synthesis that has collated data from patients who have had bariatric surgery. This qualitative synthesis by Coulman *et al.* (30) explored patients' experiences of living with the outcomes of bariatric surgery and the psychosocial impact of this type of surgery. The authors identified three central themes: control, normality and ambivalence, and their findings demonstrated the importance of follow-up support to help patients cope with the psychosocial impact of their surgery (30). Our findings are in agreement with their

conclusions, but give further insight into patients' experiences, feelings and preferences for their longer term follow-up care.

Strengths

By performing a qualitative synthesis we were able to aggregate data from multiple countries and a large number of patients. Since there are relatively few primary qualitative studies in the area this review therefore represents the best current evidence on patients' experiences of longer term follow-up care and allows insight into the enablers and barriers to attendance at longer term follow-up appointments.

Our findings are of clear relevance to the development of effective, patient centred follow-up care. Given that good follow-up care is key to optimising health outcomes for these patients this review could contribute to improving the longer term effectiveness and cost-effectiveness of bariatric surgery. Several clinical guidelines for the care of patients following bariatric surgery have highlighted the role primary care HCPs will have in the longer term care of these patients (1, 3). In the UK, guidance has also been published on suggested shared care protocols (15), but these are not widely used. Indeed, around a third of areas do not have a local specialist service (64), and training on post bariatric care for GPs is lacking. Here we were able to synthesise data on patients' interactions with GPs, which are rare in the current literature and to give insight into some of the issues implementing these guidelines within primary care from a patient perspective.

EASO guidance (3) does also discuss some of the other issues raised in this review, with recommendations that patients are counselled pre-operatively including the risk of alcohol abuse, and emphasising the importance of the availability of long term specialist multidisciplinary care, including patient support groups and psychological support post-operatively. Our findings therefore support current clinical guidance (1, 3, 16, 65) as well as being aligned with the "Too Lean a Service?"

report (66), which states that long term follow-up care is critical for this cohort of patients. NICE guidance [CG189] highlighted the need for research investigating effective behavioural interventions for patients following bariatric surgery (1) and our findings support the need for these studies to be conducted as well as providing insight into patients' needs when developing such interventions.

Limitations

This was a rapid review and so only a limited number of databases were searched. We included some studies where patients were on average more than 12 months post-surgery so we may have unintentionally included some views from patients who were earlier than this in their post-surgery journey. The majority of the studies did not have follow-up care as their main focus which may have limited the data available and thus the richness of our interpretation. In particular, there were surprisingly little data on bariatric dietitians. There were also little data on bariatric surgeons, but this is less unexpected as their role tends to be more prevalent in the pre and peri-operative periods than longer term post-operatively. Most studies did not report data on the duration of the follow-up care programme experienced by study participants (Table 1). This may therefore limit interpretation of patients' comments due to a potential lack of context.

Conclusions

This review highlights the complexity and continuing medical, nutritional and psychological needs of patients following bariatric surgery. We have identified barriers and enablers to attendance as well as preferences regarding components of longer term follow-up care after bariatric surgery. In addition, this review has highlighted key gaps in current evidence. There were relatively few primary studies exploring patients' experiences of longer term follow-up care as the main focus of the study. The findings of this review suggest that from the patient perspective there is a need for continued support from knowledgeable HCPs beyond two years post-surgery for a variety of issues that

patients can find themselves contending with in the longer term. Given the range of potential issues it is likely that an array of services and types of support are needed.

Recommendations

Primary qualitative studies are now needed that focus on exploring in depth patients' needs and preferences for their longer term post-bariatric care, as well as, factors affecting their attendance at longer term follow-up care appointments. More research is also needed into what longer term follow up is actually being received by patients who have been discharged to primary care, and whether primary care teams are trained and able to deliver the appropriate care.

List of tables and figures

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