

Review

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A review of mothers' prenatal and postnatal quality of life

Andrew Symon*

Address: School of Nursing & Midwifery, University of Dundee, Dundee, Scotland, UK

Email: Andrew Symon* - a.g.symon@dundee.ac.uk

* Corresponding author

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Abstract

Background: Contemporary broad descriptions of health and well-being are reflected in an increasing appreciation of quality of life issues; in turn this has led to a growing number of tools to measure this.

Methods: This paper reviews articles cited in MEDLINE, CINAHL and BIDS which have addressed the concept of quality of life in pregnancy and the period following childbirth.

Results: It describes five groups of articles: those explicitly assessing quality of life in this area; those using broader health assessments as an indicator of quality of life; those articles equating quality of life with certain pregnancy outcomes in identified groups of patients; those studies which identify the possibility of pregnancy as an outcome measure and infer from this that quality of life has been improved; and those articles which are themselves reviews or commentaries of pregnancy and childbirth and which identify quality of life as a feature.

Conclusions: The term 'quality of life' is used inconsistently in the literature. There are few quality of life tools specifically designed for the maternity care setting. Improved or adversely affected quality of life is frequently inferred from certain clinical conditions.

Review

The traditional narrow definition of health (in terms of mortality and serious morbidity) has been replaced by a much broader definition which encompasses "physical, mental and social well-being, and not merely the absence of disease or infirmity" [1]. Steadily decreasing maternal and perinatal mortality rates in developed countries over the last few decades have led to a growing expectation that pregnancy and childbirth should at the very least result in a live mother and baby. While such outcomes are expected in many countries, they can never be taken for granted, and the corresponding levels of dissatisfaction when the clinical outcome is poor have resulted in rising levels of complaints and litigation.

Nevertheless, the focus of antenatal care in developed countries has expanded from its traditional aim of preventing, detecting and managing problems and factors which might adversely affect the health of mother and/or baby [2]. It now includes broad aims such as "to support and encourage a family's healthy psychological adjustment to childbearing", and "to promote an awareness of the sociological aspects of childbearing and the influences that these might have on the family" [3]. This broader approach echoes the development of 'quality of life'-focussed assessments in the wider field of health care. Within maternity care, one of the main areas of interest to researchers has been women's satisfaction levels with their care [4]. However, this reliance on gauging satisfaction levels for both antenatal and postnatal care has recently

been criticised [5], particularly when this approach is used as a driver for planning the future provision of services.

Perhaps surprisingly, given the growth of quality of life scales in other areas of health care, there has until recently been no tool specifically devised for general use in the maternity care setting. This situation has been rectified recently with the development of the Mother-Generated Index [6,7]. Some of the hesitation in developing such a tool may have stemmed from the slightly ambivalent position of maternity care in developed countries. Perhaps uniquely in the health care setting, the context is generally not one of disease but of normal physiology. However, despite this lack of a specific tool, a number of studies have commented on women's quality of life, particularly during pregnancy. This paper now reviews articles identified by MEDLINE, CINAHL and BIDS which contained the terms 'quality of life' and either 'pregnancy', 'antenatal' or 'postnatal' in their abstract or title.

Specific quality of life studies in maternity care

Dow *et al* [8] assessed quality of life and treatment outcome among three breast cancer patients treated with conservative surgery and radiation in the USA. They compared the results for these women, who had become pregnant, with those of 23 matched patients who had not become pregnant. Ferrans and Powers' Quality of Life Index [9] was used in conjunction with the Adaptation to Surviving Cancer Profile, and the Parenting Stress Index. Ferrans [10] claims that "quality of life depends on the unique experience of life for each person. Individuals are the only proper judge of their quality of life, because people differ in what they value." Dow *et al* concluded that family issues had the greatest impact on quality of life, and that women who became pregnant following breast cancer treatment were not at higher risk for parental stress than the normal population.

Shulman *et al* [11] report a case study of one woman with Parkinson's disease in the USA who became pregnant. They used quantitative neurologic and quality-of-life scales in the antenatal, intrapartum, and postnatal periods, but do not specify in the abstract which QOL scale was used. Unfortunately this journal was not available to the author.

Magee *et al* [12] report the development in Canada of a 30-item 4-domain health-related quality of life questionnaire for women suffering nausea and vomiting in pregnancy. The four domains are physical symptoms/aggravating factors, fatigue, emotions, and limitations. Their study population consisted of 500 women who had called a telephone help line for those experiencing nausea and vomiting in pregnancy.

Feeny *et al* [13] compared the health-related quality of life scores of 126 women undergoing either chorionic villus sampling or amniocentesis in Canada. They conducted a series of interviews (at 8, 13, 18, and 22 weeks gestation), but do not specify in their abstract which tool was used for this, and again this journal was unavailable to the author.

Other studies mention the effect of pregnancy on quality of life in certain circumstances. Coffey *et al* [14] examined the impact of pregnancy (as well as of dietary restrictions and preoperative diagnosis [ulcerative colitis vs. familial adenomatous polyposis]) on 64 patients undergoing ileal pouch-anal anastomosis in Ireland. They concluded that women who had pregnancies after this surgery had the lowest quality of life scores (as measured by the Cleveland Global QOL score), reflecting the importance of non-pouch-related factors after ileal pouch formation.

The only report of a tool specifically devised for use related to pregnancy or the period following childbirth is one devised and tested in two phases in Scotland by the author (study samples were $n = 103$ and $n = 102$) [6,7]. The Mother-Generated Index is devised for use in the postnatal period; in this single-sheet three-step questionnaire the mother identifies what is most important to her quality of life having had a baby, and scores these areas. Based on the Patient-Generated Index [15], the idea of this tool is to get away from pre-defined lists of variables or symptom checklists, and instead ask the mother what she thinks. The intention is to identify her experience and reflect her sense of values about those aspects of her life which she says are important. Intended for use along with standard checklists of physical or psychological well-being, the belief is that this approach will encourage a more holistic view of the woman in question.

Studies citing quality of life in the abstract, and using other well-being assessment tools

A number of studies have examined quality of life (QOL) through the perspective of other assessments of well-being, the most frequently cited tool being the SF-36. This is described by the Medical Outcomes Trust as a 'generic instrument', as opposed to its six identified QOL tools which cover 'condition-specific' areas – adult asthma, pediatric asthma, 24-hour migraine, migraine-specific QOL, angina, and urinary incontinence.

The SF-36's eight sub-scales are: limitations in physical activities because of health problems; limitations in usual role activities because of physical health problems; bodily pain; general health perceptions; vitality (energy and fatigue); limitations in social activities because of physical or emotional problems; limitations in usual role activities because of emotional problems; and mental health (psychological distress and well-being). Quality of life may be

affected by any or all of these, but is not specifically mentioned.

Nevertheless, the SF-36 has been taken as an indicator of quality of life. Looking specifically at pregnant and newly-delivered women with HIV, Larrabee *et al* [16] aimed to describe perceived quality of life and functional status. Their study of 21 asymptomatic HIV-positive women (and 21 HIV-negative controls) in the USA used an abbreviated 30-item version of the SF-36. They concluded that perceived quality of life is lower in HIV-positive women, less so in the antenatal period, but increasingly so as "pregnancy, the disease process, and other life events specific to delivery and the postpartum period interact."

Hueston and Kasik-Miller [17] used the SF-36 ("a standard quality-of-life measure") in a longitudinal study of 125 pregnant women in the USA, referring to "serial assessments of health-related functional status". They found that only the scores relating to physical measures of health changed significantly during pregnancy, a finding of uncertain significance in terms of quality of life for a population who are essentially healthy.

Schover *et al* [18], in their US survey of 43 men and 89 women with cancer, describe the SF-36 as a "standardized measure of health-related quality of life." The generally good SF-36 scores (compared with normative data for healthy Americans of similar age) are ascribed to these patients having survived cancer and being disease-free. This study only refers to pregnancy in terms of some women fearing that it may trigger a recurrence of the cancer.

MacLennan *et al* [19] used the 1998 South Australian Health Omnibus Survey to determine the prevalence of pelvic floor disorders. They found that these were strongly associated with the female gender, ageing, pregnancy, parity, instrumental delivery, and quality of life scores. They used the SF-36 to assess these, although this is not stated in the abstract.

Ciardi *et al* [20] claim that the SF-36 "was used to describe general health status and quality of life" in their US study of eight pregnant women involved in an assessment of an antenatal exercise programme, although they make no claim about quality of life in their abstract results or conclusions.

Rumbold & Crowther [21] aimed to identify any reduction in perceived quality of life in Australian women diagnosed with gestational diabetes. They used the SF-36 (a "health survey") together with the six-item short-form of the Spielberger State-Trait Anxiety Inventory and the Edinburgh Postnatal Depression Scale. They found that

women who screened positive for gestational diabetes had lower health perceptions than women who tested negative. They were also more likely to rate their own health at a lower level, and less likely to rate their health as 'much better than one year ago'. However, the authors' conclusions are that it was these women's perception of their own health that was adversely affected, rather than their quality of life being affected.

Attard *et al* [22] used the SF-36 (which they refer to as the 'Short Form-36 QOL survey') in an observational, multi-centre prospective cohort study of Canadian women with nausea and vomiting in pregnancy. They found that scores for these women were lower in all eight domains, and that the degree of limitation was associated with symptom severity.

Apart from the SF-36, other tools have been used as an indicator of quality of life. Hunfeld *et al* [23] claimed in their Dutch study that pregnant women with a previous pregnancy loss ($n = 24$) had a lower quality of life than pregnant women who had not had such a loss ($n = 26$). This assessment was made before and after mid-trimester ultrasound scan; quality of life was "revealed" by feelings of social isolation, negative emotional reactions, and pain, although they do not specify in the abstract which tool(s) they used, and this article was unobtainable.

Aslan *et al* [24] used the International Prostate Symptom Score (IPSS), a seven-symptom assessment scale of urinary symptoms, in an assessment of 256 pregnant and 230 non-pregnant healthy women in Turkey. Their abstract mentions no other tools, and yet the abstract refers to quality of life findings. This article was unavailable to the author, and I could not ascertain whether such a finding was supported by any measurement other than urinary symptoms.

Simko and McGinnis [25] sought to describe the quality of life in 124 patients in the USA with congenital heart disease (CHD), hypothesising that advances in health care mean there are more adult survivors with CHD, and that pregnancy concerns are pertinent to this group. They used the Sickness Impact Profile, also produced by the Medical Outcomes Trust. This is described as a "behaviorally-based, health status questionnaire", covering everyday activities in 12 categories. These are sleep and rest; emotional behavior; body care and movement; home management; mobility; social interaction; ambulation; alertness behavior; communication; work; recreation and pastimes; and eating. From their findings these authors claim that the Sickness Impact Profile can be used to assess "quantitative and subjective quality of life" in adults with CHD. This assertion seems to imply that a subjective assessment could not be quantified.

Pregnancy outcome studies mentioning 'Quality of Life', but using no QOL tool

A number of articles used the term 'Quality of Life' in their abstract, but did not address it specifically. It has frequently been used in a relatively loose manner, with the assumption made that from the existence of certain circumstances one could deduce that quality of life had been improved or hindered. A number of these articles referred to a prolonged life expectancy from a radical therapy or a previously fatal condition.

Førde [26] reports a Norwegian study of 65 pregnant women which examined the incidence and significance of minor ailments during pregnancy. The abstract notes that "pregnant women's ailments may cause anxiety and reduce the quality of life". The findings indicated that certain women (notably those with psychosocial problems and heavy physical work) were more likely to report a higher number of ailments, and the author concludes that when such ailments are volunteered by women, clinicians should consider the need for psychosocial support. In this case there is an assumption that an increased number of ailments equates with a lower quality of life, although quality of life as such is not formally assessed.

Morita *et al* [27] assessed pregnancy outcome in Japanese women who had undergone renal transplantation. They claim from their analysis of eight pregnancies that "female renal allograft recipients have a better quality of life because they can safely deliver a child if they observe the criteria for pregnancy [which have been] established for renal allograft recipients." Improved quality of life is assumed because of a particular clinical outcome. Similarly, Jordan & Pugh [28] report a case study of one 22-year old woman who safely delivered a healthy infant four years after receiving a donor heart. They state that longer-term survival in heart transplant recipients has improved their quality of life, and that pregnancy – once thought to be contraindicated – can now be considered.

Miniero *et al* [29] claim that improvements in surgical techniques and immunosuppression have improved both survival and quality of life in patients who have undergone organ transplantation. This has meant that women of child-bearing age who have been the recipients of an organ transplant are now more likely to have the option of planning a pregnancy. This Italian study examined pregnancy outcome in the case of 42 women who had received a donor kidney. Crude outcome measures (type of delivery; number of live births; infant birthweight) were collected and compared with population means. The authors concluded that these women were more likely to experience spontaneous abortion and preterm delivery, and to have babies of low birthweight. However, in this study no congenital defects were identified, and infant

development appeared to be normal. This study appears to equate longer survival in these patients, and their improved chance of carrying a pregnancy to a successful conclusion, with improved quality of life. There is no report of a subjective assessment of these women, or how they interpreted these outcomes.

In a similar vein, Yamamoto *et al* [30] note that both life expectancy and quality of life have improved for people with spina bifida, and that as a result pregnancy is becoming more common in adolescent and adult female patients. From their analysis of six deliveries in Japan they note that careful urological and obstetric surveillance is required. As with the study above, the very possibility of a pregnancy resulting in a live birth seems to have been taken as recognition that quality of life has been improved for these patients.

Also in this vein, Anselmo *et al* [31] describe the cases of six women in Italy with Hodgkin's disease who, following chemotherapy and/or radiotherapy experienced precocious menopause, and yet managed to carry a pregnancy successfully to term. This was thanks to oocyte donation, in vitro fertilization and intrauterine embryo transfer or oocyte intracytoplasmic insemination. The authors assert that they "set the goal of improving the quality of life of these patients", and imply again that a pregnancy followed by a live birth represents success in these terms. Skordis *et al* [32] similarly describe a Cypriot study of pregnancy outcomes in 62 women with thalassaemia. That 81 of the 90 pregnancies ended successfully is taken as encouraging evidence of the prospect of an improvement in quality of life for this group of patients.

Shimaoka *et al* [33] sought to investigate "the quality of life during and after pregnancy of ... patients who had undergone Kasai operation." Their study involved a survey of 134 institutions affiliated to the Japanese Biliary Atresia Society. Their results indicated that even when patients with biliary atresia had made a successful recovery after Kasai surgery, unexpected complications still occurred when they become pregnant. Quality of life issues for these patients are inferred from the reports of clinical practitioners regarding pregnancy and delivery complications.

Thomas and Napolitano [34] report a case study of one 23 year-old primigravid woman in the USA who, despite opiate analgesia, was incapacitated by severe and chronic pelvic pain. Acupuncture was successfully employed, with the authors claiming that by allowing her to maintain normal activity her quality of life had been improved. While it is difficult to argue with this conclusion, again no specific quality of life measurement appears to have been made.

Mørkved *et al* [35] used a self-report of urinary incontinence as a cipher for quality of life assessment in a study of 301 pregnant women in Norway. As with the Thomas and Napolitano study, it is difficult to deny that the clinical condition described (in this case urinary incontinence) is indeed a debilitating condition which impacts adversely on a person's quality of life, but again there is no formal quality of life approach.

Studies using the possibility of pregnancy as an outcome measure

While the studies in the above section discussed actual pregnancy outcomes, for a number of other studies it is the possibility of pregnancy and childbirth, rather than their occurrence, which is taken as the outcome measure. In one sense these articles are very similar in approach, in that they discuss an outcome which, thanks to advances in medical and surgical treatment, can now be considered.

Gantt [36] describes a study of 13 women with congenital heart disease (CHD) in the USA. Similar to the Simko and McGinnis study reported above [25], it relates the concerns of young women with CHD about the possibility of pregnancy, but rather than using an established tool (Simko and McGinnis used the Sickness Impact Profile), Gantt used a grounded theory approach to address the question of 'quality of life issues'.

Geldmaker [37] claims that "Medical advances in disease management have improved quality of life for women with cystic fibrosis and now enables them to consider pregnancy." Having assumed that quality of life has been improved, the author goes on to describe how grounded theory and a 'complementarity research technique' were used to survey twelve women who had been recruited over the internet and through a cystic fibrosis newsletter. The tools used in this study were questionnaires for Demands of Illness and self-care of cystic fibrosis, followed by semi-structured telephone interviews.

Reviews and Commentaries

The above section examined research studies that had addressed the possibility of pregnancy in certain identified groups. A number of other articles concern the possibility of pregnancy, but do not approach this from the point of view of a single study. Some are more theoretical (essentially commentaries), others are reviews.

Gulati and van Poznak [38] carried out a MEDLINE review of reported pregnancies in women who had undergone bone marrow transplantation. They note that high-dose chemotherapy and radiation treatment are associated with gonadal dysfunction, and that questions of fertility are important because these patients "are often young people who wish to resume a normal quality of life,

which for many patients involves the desire to have children". Here the equation is made between having children and quality of life.

Ferrero *et al* [39] also carried out a MEDLINE review. They examined the "aetiology, epidemiology, diagnosis, clinical course, treatment and prognosis of peripartum cardiomyopathy," noting that improvements in medical care and treatment have significantly improved the quality of life and survival of those experiencing this serious complication. Schover [40] conducted a literature review concerning "cancer survivors' concerns about infertility and childbearing", as a means of generating hypotheses. Among these are that survivors diagnosed in adolescence will be more anxious about parenthood; that women will be more distressed over infertility and more concerned about their children's health than men; and that survivors who rate their overall quality of life more negatively will be less concerned about infertility and more apt to decide to forego parenthood.

Arsenault *et al* [41] conducted a MEDLINE and Cochrane database review to examine the evidence-based management of nausea and vomiting in pregnancy. They concluded that this condition has a profound effect on women's health and quality of life during pregnancy, as well as a financial impact on the health care system.

Trachter *et al* [42] present a general description of concerns of women with inflammatory bowel disease and how this impacts on their quality of life, with particular reference to partner relationships and sexual health. They include case studies as a way of revealing some of these concerns, and, in order to improve the quality of life and well-being of these women, they call for additional research to evaluate their relationship difficulties, sexual comfort, and sexual behaviours.

Several articles refer to quality of life issues in pregnancy in a very general way.

An article by Kaneko [43] entitled 'Pregnancy and quality of life in women with epilepsy' does not mention quality of life in the abstract, instead reporting that pregnant women who have epilepsy have legitimate concerns regarding the effects of antiepileptic drugs on the fetus. In this case it seems to be assumed that concerns about teratogenic effects indicate a reduced quality of life. Barry [44] claims that "ballet dancers have been observed to have increased difficulties in pregnancy and labour", and goes on to present an anatomical, physiological and social analysis. The conclusion is that with appropriate intervention from certain health care practitioners (nutritionists, doctors, nurses and midwives), "the ballet dancers' quality of life, health status and professional performance can

be improved." Quality of life does not appear to be addressed specifically.

Ostgaard [45] notes that backpain is very common in pregnancy, and claims that this "lowers the quality of life", as well as causing absence from work. The author defines back pain and suggests a method for classifying back pain in pregnancy into two different pain types. Rosenn and Miodovnik [46] describe diabetic complications in pregnancy, claiming that these "may have a tremendous impact on ... quality of life and ... ultimate prognosis." Hassey [47] notes that "Pregnancy and parenthood after treatment for breast cancer are quality of life issues that are a growing concern for long-term survivors of cancer", and calls for "a critical review of traditional opinion against pregnancy after treatment for breast cancer".

Hou [48] discusses pregnancy in women with renal insufficiency and end-stage renal disease. The author notes the possibility of transplantation, and anticipates that increasing experience in this area will lead to more successful outcomes. If this is so, then "the possibility of parenthood will be added to the improved quality of life in these women." Graham *et al* [49] note that there is a lack of awareness about the extent and effect of high levels of reproductive morbidity on the health and quality of life of women in the developing world. They go on to describe methodologies currently being developed for raising awareness at national, community, and individual levels.

Conclusions

The most striking aspect of reviewing the available literature is the lack of tools designed specifically for use in the general maternity care setting. Indeed, the absence of any such tool was one of the drivers for developing the Mother-Generated Index, which may itself now be adapted for use during pregnancy. Its subjective nature allows a wide range of topics to be raised and assessed, reflecting the belief that it is important to try and record "the total well-being of the patient" rather than focus on clinically measurable biomedical features" [50]. Magee *et al* [12] devised a health-related quality of life instrument for nausea and vomiting in pregnancy. Their approach was certainly thorough, using four sources: a focus group of women experiencing this condition was conducted by the manufacturers of a drug used in its treatment; the authors conducted a MEDLINE search; they incorporated the views of 17 health professionals experienced in this area; and reviewed several generic measures including the SF-36 and Sickness Impact Profile. They condensed their original 195 items to a 30-item questionnaire. It is possible to argue that, despite what seems to be a comprehensive approach, this still results in a 'closed list', which

might exclude issues important to some people's quality of life.

Several studies did make use of existing explicit quality of life tools, but rather more relied on more generic instruments whose relationship with quality of life is more debatable. The various descriptions of the SF-36 (which ranged from a "health survey" to "a standard quality-of-life measure") reveal an inconsistent approach which itself reflects the difficulty with defining quality of life. How much is it health-specific, or even health-related? It is revealing that the Medical Outcomes Trust has itself produced several quality of life tools and yet refers to the SF-36 as a 'generic measure'.

Staniszewska [51] notes that the term 'quality of life' is often used interchangeably with 'health-related quality of life', 'subjective health status' and 'functional status'. However, all of these approaches risk defining the issues for an individual at the expense of allowing that individual to describe what is most important to him or her. We have tried to get around this difficulty by devising a tool which allows the woman in question her own subjective and qualitative evaluation of her life, while at the same time providing a quantitative assessment. This approach is advocated by Muldoon *et al* [52], who suggest that QOL scales should measure both objective functioning and subjective well-being.

If several studies explicitly measured what they took to be quality of life, many others used the term in a very loose way, simply equating improved or reduced quality of life with a certain clinical outcome. As noted earlier, it is hard to argue that the existence of urinary incontinence does not diminish quality of life, and yet using this term without addressing its complexities more specifically is perhaps not very helpful. The individual (indeed unique) nature of quality of life is obscured by an assumption that a particular clinical outcome or condition is *de facto* good or bad for one's quality of life. We found when testing the MGI that although different women would cite similar examples (such as tiredness), the range of scores assigned to this aspect of their life was wide; in addition mothers rated them very differently in terms of their importance. We believe this approach helps to get away from a reliance on 'symptom checklists' which can overstate a problem or result in a medically-derived diagnosis with which the woman might disagree [53,54].

Author's contribution

The author was invited to submit a review on mothers' prenatal and postnatal quality of life, and carried out the literature review referred to in this article.

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