Scandinavian Journal of Primary Health Care

ISSN: 0281-3432 (Print) 1502-7724 (Online) Journal homepage: https://www.tandfonline.com/loi/ipri20

The many facets of involuntary childlessness in general practice

Wolfgang Himmel, Edith Ittner, Maike Schroeter, Michael M Kochen

To cite this article: Wolfgang Himmel, Edith Ittner, Maike Schroeter, Michael M Kochen (1999) The many facets of involuntary childlessness in general practice, Scandinavian Journal of Primary Health Care, 17:1, 25-29, DOI: 10.1080/028134399750002854

To link to this article: https://doi.org/10.1080/028134399750002854

The many facets of involuntary childlessness in general practice

Wolfgang Himmel, Edith Ittner, Maike Schroeter and Michael M Kochen

Department of General Practice, University of Göttingen, Göttingen, Germany.

Received November 1997. Accepted March 1998.

Scand J Prim Health Care 1999;17:25–29. ISSN 0281-3432

Objective – **To obtain a vivid picture of involuntary childlessness in general practice so that the doctor becomes aware of the frequency and the forms of childlessness.**
Design – **Analysis of in-depth interviews.**
Setting – **General practices in the area of Göttingen, Germany.**
Subjects – **35 patients (27 females) who described themselves as involuntarily childless.**
Main outcome measures – **Family status, reason for childlessness as seen from the patient's perspective, treatment status, and expectations towards the general practitioner (GP).**
Results – **Eleven patients had one or more children resulting, either from the present partnership or from a previous partnership. A deficient hormone status (7 patients) and tubal disorders (7) were most frequently reported by the patients. Some patients reported several reasons. In four cases, childlessness was directly or indirectly caused by problems within the partnership. Only eight interviewees or their partners were receiving active treatment at the current time. An additional eight couples had been previously treated. Medical information and emotional support were most often expected from the GP, but not always received – because of lack of time, lack of trust or lack of initiative on the doctor's part.**
Conclusions – **Since social reasons, problems with the partnership or anxieties may cause childlessness or may be associated with somatic causes, the GP should consider infertility in the broader context of family medicine. Although not all childless patients do expect immediate diagnosis, referral and treatment for their condition, they are often waiting for the GP's initiative to talk about their problems.**

Key words: **infertility, family practice, qualitative interviews, psychology.**

Wolfgang Himmel, MD, Department of General Practice, University of Göttingen, Robert-Koch-Str. 42, D-37075 Göttingen, Germany.

''Infertility'' and ''sterility'' are medical concepts used to describe and explain problems of becoming pregnant in due time (1). The most important causes of female infertility are ovarian dysfunction and disorders of the tubes and the uterus. Male infertility is predominantly caused by cryptorchism, aplasia of the epididymis, varioceles and endocrinological and chromosomal abnormalities. About 30% of all cases involve both male and female factors or are of unknown aetiology (2,3).

In the case of infertility, the general practitioner (GP) is responsible for early referral of the couple to specialist services or may perform the first examination and manage any hormone therapy recommended by a fertility clinic (4). He or she is ideally placed to provide valid information about the risks of fertility treatment and to give emotional support during treatment and in the case of treatment failure (4–6). These functions refer to the characteristics of family medicine (7).

In addition to clearly defined samples of patients diagnosed as infertile, GPs will find a much broader variety of involuntarily childless couples in the practice population, including non-medical or not clearly defined reasons for childlessness. Some patients will probably never talk to doctors about their desire to have children or may have problems in deciding whether or not they should seek medical help (8). Some will be in need of a communication partner to clarify whether they really wish for a child. With respect to this variety of patients it may be more appropriate for GPs to speak of *involuntary childlessness* instead of using the medical term infertility.

To obtain a vivid picture of involuntary childlessness in general practice, we studied a sample of patients who positively answered a short screening question as to whether they would like to have a child. In a subsequent interview we attempted to find out more about their family status, the reasons for their childlessness – as seen from their point of view – , their treatment status and their expectations towards the doctor. This should prevent the GP from underestimating the problem and the frequency of involuntary childlessness in his or her practice population.

METHODS

Participants

Over a period of one to two days, two research assistants visited 21 general practices in the wider area of Göttingen (a town of 130000 inhabitants and

its rural municipalities located in the north of Germany). The practices were randomly selected out of a group of 53 general practices which took part in a larger study on involuntary childlessness. These practices represent 72% of all general practices in the Göttingen area. The research assistants asked all patients aged 20–54 years on these days several questions concerning their actual family situation and potential desire to have children (''short screening''). If patients reported that they had or had had an unfulfilled desire for a child, they were asked to participate in a longer interview (informed consent). The short screening procedure was continued until 35 patients were enrolled. This sample size was considered adequate to cover the broad range of different reasons for childlessness (''point of redundancy or theoretical saturation'') (9).

Data collection and analysis

Since childlessness is a complex condition – as to the reasons and consequences – we decided to carry out open interviews that may allow patients to describe their situation in detail and that may reduce fears and stress in the course of the interview. An interview guide was used, comprising the following main topics:

- the patient's present family situation
- medical and non-medical reasons of childlessness from the patient's point of view
- treatment status
- expectations towards the GP.

Patients' statements were recorded – as literally as possible – by hand. These handwritten records were transcribed and processed the same day. We ordered the written material according to the three main aspects. The diverse reasons for involuntary childlessness, sometimes scattered throughout the interview, were independently analysed by three researchers (WH, EI, MS). We summarised patients' statements by descriptive coding to explicate how patients understand and define their situation (10).

The authors were trained and experienced in qualitative interviewing techniques. Due to the private nature of the issue of childlessness, we decided not to record, but learned how to concentrate on the patient's history while taking down the minutes.

RESULTS

Patients

From June 1995 to October 1996, a total of 1327 patients (525 male and 802 female) were screened in the participating practices. Of these, 49 patients who had positively answered the statement that they had a desire for a child, or made some indications that could be interpreted in this sense, were asked for a longer interview. Six of the patients had to be excluded later because their answer was based on a misunderstanding. Eight patients refused to participate in the subsequent interview. Seventy-seven percent of the remaining 35 patients were female. On average, the patients were 35 years old (median). Most patients were workers or employees. Compared to national data, no differences could be detected with regard to their education (Table I).

Family situation

Twenty-three patients (66%) had no children, neither from the present nor from a previous partnership (Table I). Twelve patients had one or more children, either from the present partnership (five persons) or from a previous partnership.

Reasons for involuntary childlessness

Twenty-two patients described the reason for their childlessness in a way that it could be ''translated'' into a medical diagnosis (Table II). A deficient hormone status (20%) and tubal disorders (20%) were most common. Some patients reported several reasons. Three examples may highlight the variety of problems.

> 32-year-old woman: I always wanted another child, although I had had great difficulties with the first one. It was a matter of life and death and nobody knew if she (= the daughter) would survive. The umbilical cord was

Table I. *Patient sample.*

Involuntarily childless patients	n	(%)
Age		
Mean (range)	35.6	(27–54)
Gender		
Male	8	(23)
Female	27	(77)
Children		
None	23	(66)
Own	10	(28)
Adopted	1	(3)
Adopted and own	1	(3)
Occupational status		
Worker	9	(26)
Employee	15	(43)
Disabled/unemployed	3	(8)
Housewife	6	(17)
Student	2	(6)
Education years		
9 (Primary)	13	(37)
10 (Lower Secondary)	13	(37)
13 (Upper and Post Secondary)	9	(26)

Table II. *Reasons for childlessness and treatment status.*

Pat.	Sex	Age	Reason for childlessness[1]	Treatment status
1	w	31	Ectopic pregnancies; tubal obstruction	Hormone treatment, tubal surgery
2	w	30	Genetic risk for another disabled child	–
3	w	43	Partner's refusal in first partnership; unknown for second partnership; abdominal pain; now post hysterectomy	Analgetics
4	w	31	Unknown; "sudden hearing losses"	Homeopathic treatment
5	w	33	Unknown; stress; now breast cancer	Basic diagnostics
6	w	37	Ectopic pregnancy; deficient hormone status; age	Basic diagnostics
7	w	32	Fear of birth complications (first child: premature birth)	–
8	m	46	Ovulation disorders and age of the female partner; medical indication for sterilisation of the female partner	none; refertilisation discussed
9	w	33	Ovulation disorders; male subfertility	Hormone treatment; sex on demand
10	w	37	Ovulation disorders	Basic diagnostics
11	w	36	Tubal obstruction; seminal irregularities	Basic diagnostics; sex on demand; tubal surgery planned
12	w	42	Partner's refusal	–
13	w	36	Unknown in first partnership; tubal obstruction; deficient hormone status	Tubal surgery; sex on demand; hormone treatment
14	w	52	Partner's refusal; age; unilateral ovarectomy and hysterectomy	–
15	w	29	Genetic risk for another disabled child	–
16	m	29	Tubal obstruction and deficient hormone status of the female partner	Tubal surgery; basic diagnostics; sex on demand
17	w	40	Manic depression; fear of a disabled child	–
18	w	29	Deficient hormone status; vaginal bleedings; abdominal pain; endometritis	Basic diagnostics; homeopathic drugs
19	m	35	Irregular menstrual cycle of the female partner; unknown	Homeopathic drugs
20	w	54	Emotional blockade; a too long period of oral contraception; unknown; too old nowadays	Homeopathic drugs
21	w	41	Subfertility of the first partner; concentration on profession; age	–
22	m	38	Unknown; oral contraceptives too long	Laparascopy; IvF
23	w	37	Tubal obstruction	Laparoscopy; hormone treatment; IvF
24	m	36	Tubal obstruction	Hormone treatment; intrauterine insemination
25	w	32	Subfertility of the male partner; fear of cancer (genetic risk)	Laparoscopy; IvF
26	w	32	Reasons of mind: finances, examination	–
27	m	37	Unknown; semen analysis planned	Sex on demand
28	m	34	Unknown; stress caused by shift work	–
29	w	31	Male partner's sterility	ICSI
30	w	27	Hormone status; sudden hearing loss	Basic diagnostics; hormone treatment
31	w	37	"Everything OK"	(Basic diagnostics)
32	w	35	Male partner's refusal (2 children from his first partnership)	–
33	w	29	Still-birth; "the fear remains"	Sex on demand
34	w	32	Deficient hormone status; fear of another ectopic pregnancy; male subfertility; antisperm antibodies in cervical mucus	Hormone treatment; intrauterine inseminations
35	w	33	Miscarriages; tubal obstruction; fear of another miscarriage; unknown	Alternative treatment of scara

[1] As reported by the patients.

clamped in utero; she almost starved, the doctors told me. I was rather down at this time; something remains. The fear is always present: will it happen once again? First of all, I must come to terms with myself. This will probably take two or three years…Sometimes my husband says: "Stop taking the pill!" However, it's my decision!

33-year-old woman: It is at least ten years that I wish to have a baby. We really started trying four years ago, since we married. My husband is head of the department and is under great pressure, and we thought this was the reason why it took so long.

31-year-old woman: It's because of me. I had several surgeries, nearly every year. I had several cysts and a prolapsed uterus and last year I had an ectopic pregnancy again. And now I am just considering what sacrifices are involved with having a child.

One woman expressed an intending wish for a child but hesitated because of her social situation (shortly before her college exams); she suffered because of this dilemma. In four cases, childlessness was (directly or indirectly) caused by partner problems. This was typically reported by women whose husbands refused to contribute to a successful pregnancy.

> 52-year-old woman: First I discontinued the pill and then the trouble started. My husband always says that he suffers from nausea and headaches – all that stuff women usually report. It took me half a year to realise: that he always uses the same old trick. Everything he put forward was rubbish. Today, I know he did not want to go to bed with me after I stopped the pill. We consulted a family therapist. After six sessions it was clear: an adoptee or foster child! At this time I was 35 years old and so I accepted the compromise. Several months later, a social worker phoned us and asked if we would like twins. And then he (my husband) started up again: he would be the sole breadwinner and so on. And I again backed down…We had a good sexual life in the first ten years of our marriage…until I wanted a child. Then it went down hill.

Two couples decided not to have children because of genetic risks; the patients, however, articulated a strong desire for a child and did not rule out pregnancy forever.

> 30-year-old woman: It's a bit tricky this desire to have a child. I had a child and it died in its first year of life. We have a hereditary disease in the family. Emotionally, we would like to have a child, but rationally it does not work. If we had not always considered it over again and over again, we certainly would have had another child. There is a 25% chance that another child would be affected and would die.

Treatment status

Only eight interviewees or their partners were under treatment at the time of the interview. An additional eight couples had been treated previously. Hormone treatment (20%) and/or "sex on demand" (14%) was most often reported (Table II). Two couples were just considering seeking medical advice and treatment. The remainder refused any treatment or the reason for their involuntary childlessness was beyond the scope of medical treatment:

> 37-year-old man: It's been about five years now that we have had a desire for a child. My wife consulted a gynaecologist for a check. Then we considered what to do. Actually, we wanted to have this child in a natural way. The doctor told us what to do. We tried it by following her temperature curve but it didn't work. At this time being we do nothing. Perhaps we succeed nevertheless.

Expectations towards the doctor

Some patients considered the GP to be a medical counsellor and source of information. Emotional support and an open atmosphere for discussing problems were also highly valued. During the interview, some patients made clear that they were in need of help but did not receive it from their doctor – because of lack of time, lack of trust or lack of initiative on the doctor's part:

> 29-year-old woman: My family doctor gave me the referral to the university hospital. He told me that one should not only rely on [the options available in hospitals], but that one should also consider other possibilities…I really appreciate his drawing my attention to the alternatives.

> 32-year-old woman: Perhaps one also lacks the courage required to approach him or her about this matter. Perhaps it would be good if he or she were to meet one halfway.

> 35-year-old man: I would not consider that bad. At an age in which one normally has a wife and children. Perhaps it would be good to find out what one really would like to do.

DISCUSSION

The medically based view on the different reasons for infertility may give GPs a narrow-minded image of the infertile couple. Since social reasons, problems of partnership or anxieties may cause childlessness or may be intermingled with somatic causes, the GP should consider infertility in the broader context of family medicine (11). Some authors, therefore, use the term "social infertility" for these conditions (12).

The infertile couple is not necessarily childless. About one-third of the patients or their partners in the study had children. In some cases, these children stemmed from their present partnership, a condition defined as secondary infertility (1). In other cases, the patient or his/her partner had children from a former partnership, some of them living in the present household. These examples should remind the GP that couples with children may, nevertheless, still suffer from an unfulfilled desire for a child.

The present discussion about infertility is strongly influenced by the power of reproductive technologies (13), suggesting that the infertile couple just has to wait to be treated by the most advanced methods. Many patients in our sample, however, terminated fertility treatment or decided against a treatment on basic principle. However, they had not given up their desire for a child. This would falsely make the GP think that treatment refusal can be equated with the end of the problem or the episode of infertility. The doctor should also consider that not all childless patients expect immediate diagnosis, referral or treatment for their condition.

Prevalence rates for involuntary childlessness range from 3% to 26% depending on the definition of infertility (i.e. on the time span involved in the failure to conceive or if it is restricted only to unresolved

problems of infertility) (3). The rate of involuntarily childless women in our survey was 3.4%, including non-somatic reasons for childlessness, which was within the range of epidemiologic data (8,14). Since involuntary childlessness has a social stigma and poses a psychological burden for many couples (15–17), patients may be reluctant to openly discuss this condition. This seems to be especially true for the male patients surveyed, who represent a prevalence of only 1.5%. The GP, too, may be in danger of underestimating the frequency of involuntary childlessness in his or her practice population because some patients are waiting for the doctor's initiative to discuss emotional problems that arise from their childlessness.

In conclusion, the results of the study demonstrate that the typical definition of the GP's role in the management of infertility (i.e. screening, advice, referral, coordination of and cooperation in treatment) (4) cannot be applied to all couples. In contrast to patients seen in infertility clinics, GPs are confronted with the entire variety of involuntary childlessness. Since some of these patients have children, refuse fertility treatment, and hesitate to approach their GP, the doctor is not necessarily aware of their problems. Consequently, a more active role is required from the GP in many instances.

ACKNOWLEDGEMENTS

This work was supported by Grant 01 KY 9302 from the Federal Ministry of Education, Science, Research and Technology, Bonn, Germany.

We are very much indebted to the patients who frankly discussed their problems with us in the interview.

REFERENCES

1. World Health Organization. The epidemiology of infertility: report of a WHO scientific group. Genf: WHO Technical Report Series no. 582,1975.
2. Mosher WE, Pratt WF. Fecundity and infertility in the United States: incidence and trends. Fertil Steril 1991;56:192–3.
3. Himmel W, Ittner E, Kochen MM, Michelmann HW, Hinney B, Reuter M, et al. Management of involuntary childlessness: a review. Br J Gen Pract 1997;47:111–8.
4. Grimshaw J, Emslie C. Managing infertility – the GP's role. Practitioner 1994;238:586–90.
5. Frey K, Dodson W, Andolsek K, Klein J. Infertility: a family practice approach. J Fam Pract 1988;5:499–505.
6. Ittner E, Himmel W, Kochen MM. Management of involuntary childlessness in general practice – patients' and doctors' views. Br J Gen Pract 1997;47:105–6.
7. McWhinney IR. A textbook of family medicine. New York, NY, Oxford: Oxford University Press, 1997.
8. Schmidt L, Münster K, Helm P. Infertility and the seeking of infertility treatment in a representative population. Br J Obstet Gynaecol 1995;102:978–84.
9. Kuzel AJ. Sampling in qualitative inquiry. In: Crabtree BF, Miller WL, editors. Doing qualitative research. Newbury Park, CA: Sage, 1992:31–44.
10. Miles MB, Huberman AM. Qualitative data analysis: an expanded sourcebook. 2nd ed. Thousand Oaks/Calif., London: Sage, 1994:55 ff.
11. Smilkstein G. The family in family medicine revisited, again (editorial). J Fam Pract 1994;39:527–31.
12. Helfferich C, Küppers-Chinnow M. Prevalence of and coping with fertility disorders. In: Federal Centre of Health Information, editor. Contraception, conception, children or none. Cologne: Federal Centre of Health Information (in German), 1996:113–36.
13. Ten Have H. Letters to Dr. Frankenstein? Ethics and the reproductive technologies. Soc Sci Med 1995;40:141–6.
14. Gunnell DJ, Ewings P. Infertility prevalence, needs assessment and purchasing. J Public Health Med 1994;16:29–35.
15. Kredentser JV. Infertility. A review of physical and emotional aspects. Can Fam Physician 1986;32:1651–5.
16. Whiteford LM, Gonzalez L. Stigma: The hidden burden of infertility. Soc Sci Med 1995;40:27–36.
17. Menning BE. Infertility: a guide for the childless couple. New Jersey: Prentice-Hall, 1977.